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## ABSTRACT

The handbook gives guidelines for the development, operation, and evaluation of a community based system of residential facilities for mentally retarded (MR) persons. Directions are given which explain the step-by-step procedure for planning in any community. The idea of a residential service delivery system is described in terms of small unit-homes, basic principles, and program flexibility to aid development of MR persons in the mainstream of the community. Specified are procedures for collecting information on individual needs before planning group homes such as child or vocational development homes, and residences for the elderly. Getting started is said to involve activities such as defining the problem, making a survey, planning a budget, and presenting a solution to the problem. Noted is the need for help from groups such as local social and governmental agencies, and trade unions. Suggested for laying the groundwork to move bureaucracies are public education strategies such as targeting the audience and using the most direct communication medium. Guidelines for getting what is needed cover legislation, financial support, and restrictive codes. Included among aspects of service administration are development of a coordination mechanism, analysis of in-home activities, and provision for volunteers in each facility. Considered for operating the program are procedures for resident selection and education, and staff education. The evaluation process is said to include establishment of criteria and responsibility for regular monitoring of services. (Included in appendixes are a community services checklist and sample planning budgets for community families of varying numbers.) (MC)

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# **The Right to Choose**

**Achieving Residential Alternatives in the Community.**

October, 1973

the Residential Services & Facilities Committee  
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General Federation of Women's Clubs  
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**National Association for Retarded Citizens**

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## How to Use This Handbook

There is *no* single recipe for developing appropriate services. There are, however, guiding principles to direct your thinking and to use in evaluating the service you develop.

This handbook has been arranged to reflect the most probable sequence of activities in developing a community-based residential service.

Even though a step-by-step process is presented in this handbook, it is necessary to remember that each community has unique individual needs, resources and personalities. No one knows more about your community than you can know.

By following the approach outlined in this handbook you are more likely to develop a logical and ethical plan.

The handbook is designed to help you develop insight into areas of necessary activity which might otherwise have escaped your attention. For this reason, study the entire handbook first and then be sure to digest the summary checklists provided at key points throughout the text.

Use the references to explore those areas which are unclear to you. Contact those groups and agencies who have been involved in successful programs.

The guidelines presented here are necessarily brief, but present the central issues and concerns to guide you and your Association in the planning and implementation of community-based residential services.

You will find that most projects which attempt to secure increased residential services in a community will require that you go through a process similar to that presented here. It may be that because of a particularly good community situation you will be able to bypass some of the indicated steps. As you have an increasing number of projects which are successful, you will naturally find less community resistance and will be able to accomplish your task in a much shorter time. The dynamics of the process of social change indicate that no two projects will be alike.

It may be that you will encounter unexpected difficulties which are not included in the discussions here. No one can do your job for you. You know your community; you know its interests and its attitudes. Some of you may have a very difficult road ahead of you, but that does not mean that you should not undertake the process. The more difficult your task, the more urgent it is that you should get underway with it. The delivery of better services to retarded persons is what drives us all in this work.

Again, we point out that this handbook merely indicates one way of going about doing things. It is based on the experience of many others who have attempted to develop community-based residential services, and succeeded.

The important thing in this extremely serious game is that you play to win. Analyze your problems and set about trying to solve them in any ways which are appropriate to your needs and your community. We hope this handbook will offer you some small help in that work.

# I. Getting The Idea



## I. Getting The Idea

One of the greatest rights and richest joys of being American citizens is that we are free to choose. We choose what we will do for a life's work, we choose our partners in marriage and in business, we decide where we will live and what lifestyle we will adopt.

As Americans we are guaranteed the pursuit of happiness, and much of the happiness derives from having a wide range of choices.

However, a retarded citizen, even though he is an American, finds he is faced with a much narrower range of choices. He is not free to live where he wishes, in the style which he desires. Systems of care tend to be limited in their variety, and in some communities the retarded citizen may be restricted to a very few choices, such as continuing to live in the home with his parents, or moving into a relatively large institutional setting. This is like offering an average young American the choice of staying with his parents or living in a college dormitory forever, a "choice" which is really no choice at all, and a situation which most Americans would find intolerable.

When there are no options, the system which exists, no matter how good or bad, is *reinforced* by having more and more money spent on it.

The right to live within one's own community and in facilities which offer access to good programs as well as adequate care, is essential to growth and dignity. Adequate community-based residential services keep the individual in his own community and forestall or eliminate the need for extended residential living.

Basic to the concept of keeping the handicapped individual in the community and as close to home as possible, is the concept of the community as the focal point for the delivery of care, treatment, education and recreation services. The first concept cannot easily be achieved without the second.

Individuals who may not be able to live with their families while receiving educational or medical services need not be sent great distances to state or private institutions. Community housing facilities permit the individual to live close to his family. Community housing can also facilitate the provision of other needed local services.



When Richard moved from the state institution he was a very shy young man, who rarely approached another person, or spontaneously started a conversation.

After his involvement in community programs and as his social life expanded, his concern about dress and personal appearance also developed.

Several months ago this young man addressed a group of 50 recreational professionals on the subject of community recreation for mentally retarded persons. Presently, after auditioning in competition with regular performers, Richard is playing a role in a community little theatre.

Current scientific knowledge, in addition to the moral considerations, demands that the human service delivery system be humanized and normalized in order to avoid the destructive individual and social consequences associated with restricted access to opportunity.

The ongoing process of development requires a flexible living environment.



Planning should lead toward:

- Establishment of small home-like units, and
- Selective utilization of the full range of services available to the community.

During the past several years an increasing emphasis has been placed on the development of community-based residential services, often in the form of small group homes, boarding homes and apartments. Alternatives such as these have the potential of providing the mentally retarded individual and his family with a series of options — options which are essential to the continued development of the entire family. The learning environment is expanded, the limits on opportunity are dramatically reduced and the community's resources are more appropriately used. The economic gains to the community have been documented, both in terms of human resources and costs of operation.

#### COMPARISON OF COSTS FOR LIFETIME SERVICES\*

● Placed in Institution (Type I) at age 6 for lifetime (till 65 @ \$5,252 per year)	\$309,868
Placed in Institution (Type II) for lifetime (till 65 @ \$12,118 per year)	714,962
Based on per diem costs FY 70	
● Mildly retarded, lives at home, becomes independent	
Preschool, 2 years (\$1,000 per year)	\$ 2,000
School, 5-18, EMR (\$700 per year)	9,100
Transitional Workshop, 18 mos. (\$1,600 per year)	2,400
	\$ 13,500
● Mildly retarded without suitable homes, in small group homes	
Community Services	\$ 13,500
Boarding Home, 6-16 (\$2,500 per year)	25,000
16-18 (\$1,700 per year)	3,400
Hostel, 18-20 (\$1,700 per year)	3,400
	\$ 45,300
● Moderately retarded with home, community services	
Preschool day training, 4-6 (\$1,600 per year)	\$ 3,200
TRM class, 6-19 (\$1,200 per year)	15,600
Sheltered workshop and extended employment, 20-26, (\$1,300 per year)	58,500
	77,300
Group homes from 35-65 (\$2,500 per year)	75,000
	\$152,300
● Moderately retarded without suitable home	
Community Services	\$ 77,300
Group home, 6-65 (\$2,500 per year)	147,500
	224,800
● Severely retarded at home	
Day training and work activity, 4-65 (\$1,600 per year)	\$ 97,600
Group home, 35-65 (\$2,500 per year)	75,000
	\$172,600
● Severely retarded in community	
Community Services	\$ 97,600
Group home, 6-65 (\$2,500 per year)	147,500
	\$245,100

\*Taken from: *Residential Study: The Georgia and Atlanta Associations for Retarded Children*, January, 1972.

A service system based upon individual need won't demand that an individual accept services he does not require. For example, not all retarded persons require a residential service, and those who do need a supervised living arrangement, do not all need the same type of residential service.

In order to make the service system economic as well as humane, it is essential that a

variety of options be available to fit the individual requirements of each child or adult.

A community's services should be available to the full cross-section of its population — retarded as well as non-retarded.

### What Is a Residential Service?

A community-based residential service is some type of housing, other than the individual's natural home, usually designed for not more than 12 persons having similar needs in terms of age, independence and/or ability.

The residential service should:

- Provide a home environment with supervision and guidance as needed;
- Afford living experiences appropriate to the functioning level and learning needs of the individual;
- Be located within the mainstream of community life; and
- Provide access to necessary supportive, habilitative and rehabilitative programs based on a developmental model of programming.

### Basic Principles

A set of principles are simply statements of the basic rules of a culture's value system. For example, the United States Constitution is a set of basic principles which serve to guide the behaviors of all citizens of the nation.

There are basic principles which underly the development of service systems to assure that those services are compatible with the nation's cultural value system and legal guarantees. These principles apply equally to all services for mentally retarded citizens.

- Retarded children and adults are guaranteed the same Constitutional rights as other children and adults and may not be deprived of life, liberty, or property, without due process of law; nor shall they be denied equal protection granted by the laws.

The courts have defined "liberty" to denote a number of different things, among which is "to acquire useful knowledge," and generally "to enjoy those privileges long recognized at common law as essential to the orderly pursuit of happiness by free men."

(Meyer vs. Nebraska, 1923)

- Traditional residential services are dehumanizing. They foster and emphasize behavior which departs from the cultural norm. Such conditions violate the dignity of the retarded person and limit his opportunity to gain "useful knowledge." Dehumanization is seen as *de facto* (actual) abridgement of the individual's basic rights, guaranteed to him by the United States Constitution.
- Retarded individuals should be treated so as to promote emotional development. They cannot be treated as children throughout their lifetimes because they are then deprived of the opportunity to learn adult behaviors.
- Programs for retarded persons must give attention to the individual's personal goals.

Most retarded men and women are capable of setting life goals and communicating their desires and aspirations. Even non-verbal retarded children and profoundly retarded adults can often participate in decision-making and goal setting if given a legitimate opportunity.

The retarded individual and the family or guardian should participate in planning for residential placement or program participation.

- Retarded children and adults should be helped to live as normal a life as possible. The structuring of daily routines, the life-style and the nature of the physical environment should approximate the normal cultural pattern to the greatest extent possible.
- Retarded children and adults are capable of learning and development. Each individual has potential for progress, no matter how severely handicapped he might be.
- The basic goal of programming for retarded persons consists of maximizing the individual's personal, social and vocational development, and as such is identical with the goal of educating and socializing *all* children and young adults. The adequacy of programs as well as of physical and psychological environments can be evaluated in terms of the degree to which they fulfill this goal.

In general this goal is more rapidly met by including the retarded individual within the mainstream of society or replicating the patterns and physical characteristics of the prevailing culture when it is necessary for a retarded person to live away from his natural home for a greater or lesser period of time.

- Specific program objectives should be tailored to meet the needs of each individual, and will vary for different degrees of impairment. The most feasible and constructive approach, in view of current limitations of knowledge, is to assume that all retarded persons have the potential for eventually leading an independent life style. This approach must dominate program planning until the individual's response to appropriate programs clearly reveals his inability to attain this goal.
- All programs for retarded persons must meet the three basic criteria of the Developmental Model:
  - a. Contribute to increasing the complexity of the individual's behavior;
  - b. Contribute to increasing the individual's ability to control his environment;
  - c. Contribute to increasing the individual's self-control and maximizing those qualities which have been culturally designated as *normal* or *human*.
- Programs for mentally retarded persons should utilize the community's existing services to the fullest extent.
- A comprehensive system of community services should be developed to provide for:
  - a. Early identification of handicaps which are developmentally disabling;
  - b. Early assistance to correct or alleviate those handicaps;
  - c. Ongoing services to the individual and his family to assure the greatest possible gains in his development.
- Community services should be strategically located throughout the state, region, or county to promote maximum social integration into the community.



### Continuum of Service

A natural consequence of the Development Model is the necessity to design all programs as parts of a continuum of service. A recognition and acceptance of the developmental and habilitation potential of every mentally retarded person requires that no program be viewed as terminal or permanent.

Every program should be part of an incremental habilitation plan geared to the needs of the individual. For each rung on the developmental ladder, there must be another rung

for the developing person to reach out to or strive for.

Each residential service facility and program should be part of a total developmental program rather than merely a place to put people.

A residential program should carefully evaluate the amount of services and supervision it will provide. To provide more services and supervision than are needed will only serve to discourage or retard the developing independence of the individual.

The goal of residential services should be to provide access to the highest possible quality of services which the retarded person needs, but at the same time to permit and encourage him to do for himself those things which he is able to do.

### Flexibility of Programs

One persistent failure of social planning is the practice of defining a social need in terms of a preconceived solution to that need.

*The Greek legend of the Innkeeper, Procrustes, who insisted that each of his guests sleep in a bed exactly the right size, is an excellent example of a "preconceived solution to a need." Since Procrustes possessed only one size of bed, it was necessary to either stretch his guests on the rack or saw off their feet in order to make them fit his bed.*

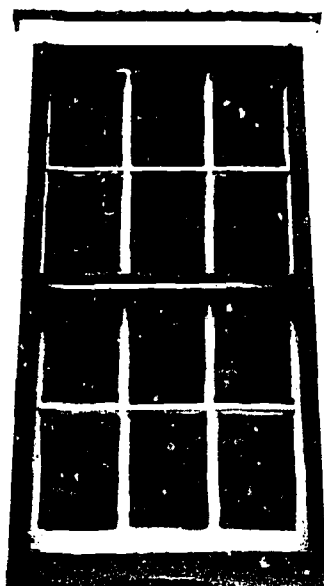
Social planning in the mental retardation field, or any other field, can no longer afford an inappropriate and simplistic approach. If any plan or any program does not meet the needs of mentally retarded persons, then the plan and the program must be changed.

The mentally retarded person should not be forced into programs which fail to meet his needs. If an individual can no longer profit from the residential services program, he must be provided with a route out of the system.

If the residential system is not able to meet the needs of an individual, then the system can be expanded to provide appropriate services to that individual or group. If the issue is primarily an environment problem, then appropriate social action can be undertaken to change that environment.

The omnipresent goal of all residential programming should be to provide maximum flexibility in all programs, so that there will be the greatest developmental gains on the part of the mentally retarded individual.

Myron, legally blind, and mildly retarded, after some 30 years in four different institutions, said with exultation on his trip to the group home for placement, "Now I won't need to act retarded anymore." His good adjustment and involvement in activities at the group home would indicate he had spent years in settings not really suited to his level or to his needs.



## CHAPTER I

### Summary

- Retarded citizens are guaranteed the same Constitutional rights as other citizens.
- The right to live within one's own community and in facilities which offer access to good programs is essential to growth and dignity.
- Planning for community-based residential services should lead toward the establishment of small home-like living units and selective utilization of the full range of services available to the community as a whole.
- A residential service should:
  - Provide a home with supervision and guidance as needed;
  - Be geared to the learning needs of the individual resident;
  - Be located within the community's mainstream;
  - Provide access to other necessary services and programs.
- The endorsement of basic guiding principles provides a method for evaluating the design and operation of a residential service.
- The goal of a residential service is to provide maximum flexibility in all programs to assure the greatest developmental gains on the part of the retarded individual.

## II. Getting the Information





## II. Getting the Information

### *What Type of Service Is Needed?*

- The comprehensive nature of a community's human services delivery system should be of such scope that no mentally retarded person has to leave his community in search of needed residential or rehabilitative services.

When considering residential services, one must constantly guard against the traditional notion that a residential placement is permanent or static.

While it may be true that many people have lived happy and productive lives, never leaving the house or environment in which they were born, it is equally true that most people do move into and out of a variety of environments as they develop their life style. The same principle holds true for mentally retarded and other developmentally disabled individuals.

Most parents would not tolerate an unchanging environment for themselves, but they frequently seek such an environment for their retarded family member. It is an error of judgment which is made from a sense of deep concern, but it is still an error.

According to the Developmental Model, every person is capable of learning and change. Retarded children or adults are, first of all, people. They can develop physically. They can grow intellectually. They can adjust socially and gain emotional maturity. They may be slower than others, but they are always capable of development. We all develop continually.

Central to the concept of the Developmental Model is the idea that the retarded person should live in a home-like environment; in fact, he should live in a home. It's normal for children to live with their parents; that's perhaps the best place for them. The next best might be near their families, but they should certainly live in places like private houses near the mainstream of society.

The same standards should be applied to these group homes as are applied to the homes of ordinary citizens. They should have the same kinds of services available to anyone else in the community.

When we think of community living for retarded persons, the idea of advancement, of mobility, of change is uppermost. A person may move from an institution to a home, to an apartment, back to the institution, if necessary; but always based on his individual need.

Many individuals and groups have attempted to define the basic elements of a residential service continuum, and there are a variety of lists which note function and design of such facilities. For the purpose of this handbook a summary from a variety of programs will serve as a springboard for your planning.

*Temporary Assistance* services is that component of the residential service network which provides temporary and crisis assistance to retarded individuals and their families. As such, it necessarily involves a range of services for all ages and all developmental levels. It may properly be conceptualized as a kind of umbrella service which must be available to all mentally retarded citizens and their families, regardless of their particular handicap.

Temporary assistance, sometimes called intermittent or respite care, is a service which developed out of an increasing need to relieve parents, on a short-term basis, of the





responsibility of caring for their mentally retarded son or daughter. Such homes may also provide care to individuals as a period of trial separation before long-term residential placement, allow for a family vacation, and provide for family crisis or emergency placement of youngsters who have no other place to live while more permanent plans are being made.

Temporary assistance often makes the critical difference in the family's ability to keep the child within the family constellation and avoid the necessity of early institutional placement.

*Life Start Programs*, like temporary assistance, involve a range of services for various ages and developmental levels. Life Start programs will provide intensive stimulation and physical therapy programs for those individuals who, whether because of their young age or because of lack of previous programming, have remained essentially bedfast or immobile.

Life Start programs are intended to serve primarily those individuals who are so neurologically or orthopedically handicapped that special medical and developmental programming is essential. They differ from regular comprehensive nursing care programs in that primary emphasis is placed upon developmental programming rather than upon mere maintenance of life services.

In addition, the Life Start program may serve as a regional facility to provide programming and treatment for specialized low-incidence disabilities such as certain metabolic diseases and progressive neurological diseases.

As is the case with all services in the residential continuum, the goal of Life Start programs will be to habilitate each individual to a sufficient degree to permit placement in more normalized programs. For younger children, this may mean placement in foster homes or child and adolescent development facilities. For some older and more profoundly limited individuals it may mean placement in homes with an ongoing nursing program.

Because of the unique role of the Life Start program in the residential service system, planning for this facility should be done in close conjunction with the community's medical centers as well as with the state and county mental retardation planning departments.

*Child and Adolescent Development* are two components of the residential services network which can be considered as one functional element in initial planning. They involve providing facilities and developmental programming for children and adolescents who have developed beyond the needs of Life Start, and whose needs, for one

reason or another, cannot be met in the natural home.

Since the children and adolescents living in these facilities will be participating in community educational and pre-vocational training programs, daytime programming in such residential settings may be minimal.

The facility should have an evening and weekend in-house program for each resident. The program would typically include development in areas such as:

- Self-help skills;
- Concept development;
- Social skills;
- Personal hygiene;
- Money management;
- Food preparation;
- Laundry maintenance;
- Planned group activities.

The activities are designed to equip the individual with experiences and behaviors required in normal everyday living.

*Skills Development* programs are visualized as a kind of connecting link in the residential services network. These facilities will serve as both a ladder out of the institutions and as a program to prevent institutionalization.

Skills Development programming will be specifically geared to meet the needs of those mentally retarded persons who lack the required behavioral skills for more independent community living. The program also serves to prepare individuals for admission to the Child or Adolescent Development home.

Skills Development can be conceptualized as encompassing three areas:

- Personal skills;
- Interpersonal skills (small group interaction); and
- Social skills (large, extended group interaction).

Although intended primarily for children and adolescents, programs for adults will also need to be developed in order that institutionalized adults can be returned to the community.



Martin is a bright-looking, 13-year-old who lived at home until he was six when he was placed in a state institution by parents who were unable to deal with his learning needs in the home. After six years in the institution, Martin was transferred to a group home in the community.

For more than a year he has been living in an Adolescent Development home with several other boys and a set of houseparents. He has made some vast improvements.

Martin attends public school classes for retarded children in the community. Although he functions very low academically in class, he has progressed to the point of a student ending his second year of schooling. Slowly but surely he has learned how to interact and make appropriate conversation; he is even willing to talk about himself. With the help of others, Martin is trying hard to become a "normal" adolescent.

Like their peers in less structured facilities, the residents of Skills Development facilities should utilize other community resources as much as possible.

Highly specialized Skills Development programs will supplement and augment rather than replace more normalized programs.

*Vocational Development* facilities are intended primarily for young adults who are actively enrolled in a vocational or pre-vocational training program in the community. These facilities are designed to be intensive training settings for those individuals who will be able to live independently or with minimal supervision upon completion of the training program.

Placement in a Vocational Development setting must not be permitted to preclude continuing academic achievement.

The program in Vocational Development facilities will be an integral part of the total vocational training program. The emphasis in these homes will be on learning of skills needed for independent living such as cooking, housekeeping, budgeting, social relations, use of leisure time, etc. Special emphasis will be placed on group interaction, group activities, dating, and so forth.

Residence in a Vocational Development facility should be brief in duration, perhaps one or two years.

During residence in these facilities, special emphasis should be placed upon the use of generic community recreational and service resources so that the retarded citizen will, when he completes his training, be able to find and use the resources he needs. Similarly, the emphasis upon family living will be decreased, and greater emphasis placed upon group and independent living, thus teaching the residents to rely less upon parents and supervisors and more upon their peers and their own decision-making and problem-solving abilities.

*Sheltered Living* homes are intended to serve individuals over the age of eighteen who require continuing assistance and supervision on a daily basis. These homes are intended primarily for moderately and severely retarded adults whose current stage of development precludes independent living.

The goal of Sheltered Living is to provide a setting in which these individuals may enjoy a more normalized life in the community as opposed to long-term placement in an institution.

In addition, Sheltered Living has as its goal to provide more severely handicapped individuals in the community with an alternative living arrangement so that they can leave home when they become adults and realize a greater measure of normalized independent living.

The program in Sheltered Living homes will focus on continuing development in self-help and self-care skills in order to increase the social competency of each person.

Every effort should be made to maintain a normalized adult atmosphere in each home, with appropriate adult tasks assigned to each resident. Residents should spend a major part of the day in workshop programs or sheltered employment, and should learn to use community resources for recreation.

*Apartment Living Training* is another connecting link in the residential services network. This program will serve as a training program for those individuals who have indicated an ability to live independently or with only minimal supervision in apartments.

Since apartment living requires skills which may not be learned in a more structured situation, the necessity of a special training program seems indicated.

The Apartment Living Training facility would typically consist of a cluster of three or four apartments for residents and one apartment housing staff teachers. The staff would work with each individual or couple on such skills as cooking, meal planning, cleaning, budgeting, relations with the landlord, use of community service resources, use of recreational resources, and so forth.

The trainees in this type of program will be taught where to go for emergency help, and how to solve many of the more intricate problems associated with independent living.

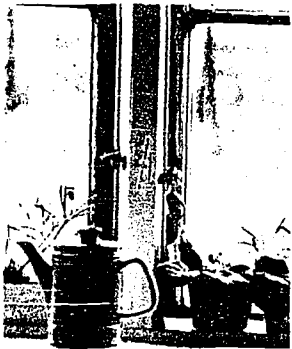
After completion of the training program, residents will be helped to select apartments with only minimal supervision, or apartment clusters where ongoing supervision could be provided by resident staff as needed.

The Apartment Living Training facility is viewed as a transitional program between Vocational Development or Sheltered Living programs and the greater independence and self-sufficiency needed for life in apartments.

In addition, the facility will also serve as a training program for individuals who have not previously resided in facilities in the residential services network, but who could profit from this kind of training prior to moving into their own apartment.

*Apartment Living* represents the final stage in the continuum from dependence to independence and from segregation to integration. It provides the mentally retarded individual with the greatest opportunity for self-sufficiency and independence of all the residential services programs.

Independent living represents a goal toward which all training programs are aimed, although it is recognized that some mentally retarded individuals may never be able to achieve this level of independence and self-sufficiency.



Bill was placed from the institution to work for \$40 per week plus room and board. The situation allowed for a minimum of free movement into the community. He later began employment at a hospital and after a short stay at a board-and-room group home, moved to a supervised apartment. Due to many years of institutional living, Bill lacked many social and housekeeping skills, but he learned rapidly.

Bill now lives in his own independent apartment. He does all his own household chores, pays his own bills and keeps his own checking account. Bill seldom needs the help of a counselor to solve his day-to-day problems for he has achieved a great deal of independence. He looks forward to the day when his efforts will be rewarded with a complete release from the institution.

Apartment living provides numerous options to vary the level of independence and amount of social integration necessary to meet individual needs.

The amount of supervision and assistance which is available to a resident of Apartment Living programs may be varied to the desired degree by:

- The proximity of the apartments to each other;
- The ratio of staff apartments to resident apartments;
- The ratio of staff members to client residents;
- The number of hours which the resident staff members and supportive personnel interact with the residents; and
- The type of supervision and guidance which are offered

The ultimate goal of apartment living is to equip the resident with the skills to meet all of his own needs, so that all dependency ties to the residential services system can be broken. This will require that the resident gradually begins to pay, from his own earnings, a greater and greater share of the cost of living in an apartment, until even financial dependence is eliminated if possible.

*Residences for the Elderly* must also be considered in the long-term planning for a residential services system.

The aged mentally retarded citizen, as is true with the population in general, frequently develops special needs with advancing age and requires a greater degree of supervision than may have been true in his younger years. For many this will initially mean moving from an independent apartment to more structured living arrangements in a sheltered living home or a residential nursing home. For others, health problems will indicate the need for intermediate or comprehensive nursing care.

### *Foster Homes*

In addition to the variety of group homes, there are other residential services which should be developed or expanded.

Many states are turning to foster home placement for adults as well as children. Where the state has a good system of home-finding and social case-work, this has been a reasonably good alternative for some individuals.

When considering foster care, one finds that there are other problems involved. Where parents have institutionalized children in order to ensure a long-term protective environment, the use of foster home placement may pose some serious adjustment problems.

Some parents find it personally and socially threatening to their own self-esteem to have their child placed in another family's home. They seem to feel that it causes them to look like failures as parents if another family is able to cope where they were not. Yet the fact that they couldn't cope must not serve as a denial of their children's right to have a home.

Parents also question the long-term stability of foster care and legitimately ask, "What will become of my child when he is elderly, and I am no longer around to assure his safety?"

Good social case-work and protective services become critical factors in the success of this alternative.

### *Nursing Homes*

The use of nursing homes as alternatives to institutional placement is perhaps one of the most controversial of all these options.

For severely disabled individuals needing nursing care, placement in existing nursing homes has been reasonably adequate so long as young adults are not placed singly in homes and so long as daily programs are provided outside the nursing homes.

With the advent of Federal assistance, nursing home placements have unfortunately sometimes been used inappropriately.

The choice of nursing homes must be done with extreme care and with assurance of adequate programs, both within the home and in the community to meet the needs of each individual.



## Conclusions

The variety of residential services discussed in the preceding pages does not necessarily represent the entire spectrum of possible options or combinations. The community's need may, for example, demand some type of rural residential five-day school to provide a residential program for those persons living in widely dispersed rural areas.

Some communities may discover the need to develop some type of facility which is designed to provide for the transformation of unacceptable social behaviors into socially appropriate behaviors. This type of service is generally for the physically mature or near-mature person whose behavior is very difficult to manage and who in some instances may exert a destructive or disruptive effect upon other residents in less structured programs. This service should provide a highly structured program and increased supervision.

The need for community-based residential services does *not* usually require a construction program. In fact, most communities contain a wide variety of existing physical facilities which can be rented, leased, or purchased. These might include larger private residential dwellings or multiple unit apartment buildings which could accommodate the needs of a variety of residents. These older homes have the added advantage of being in established neighborhoods which are usually close to transportation, recreation and shops.

Also to be considered are existing medical and hospital facilities, which operate at less than capacity and could accommodate individuals in need of medical or geriatric services.

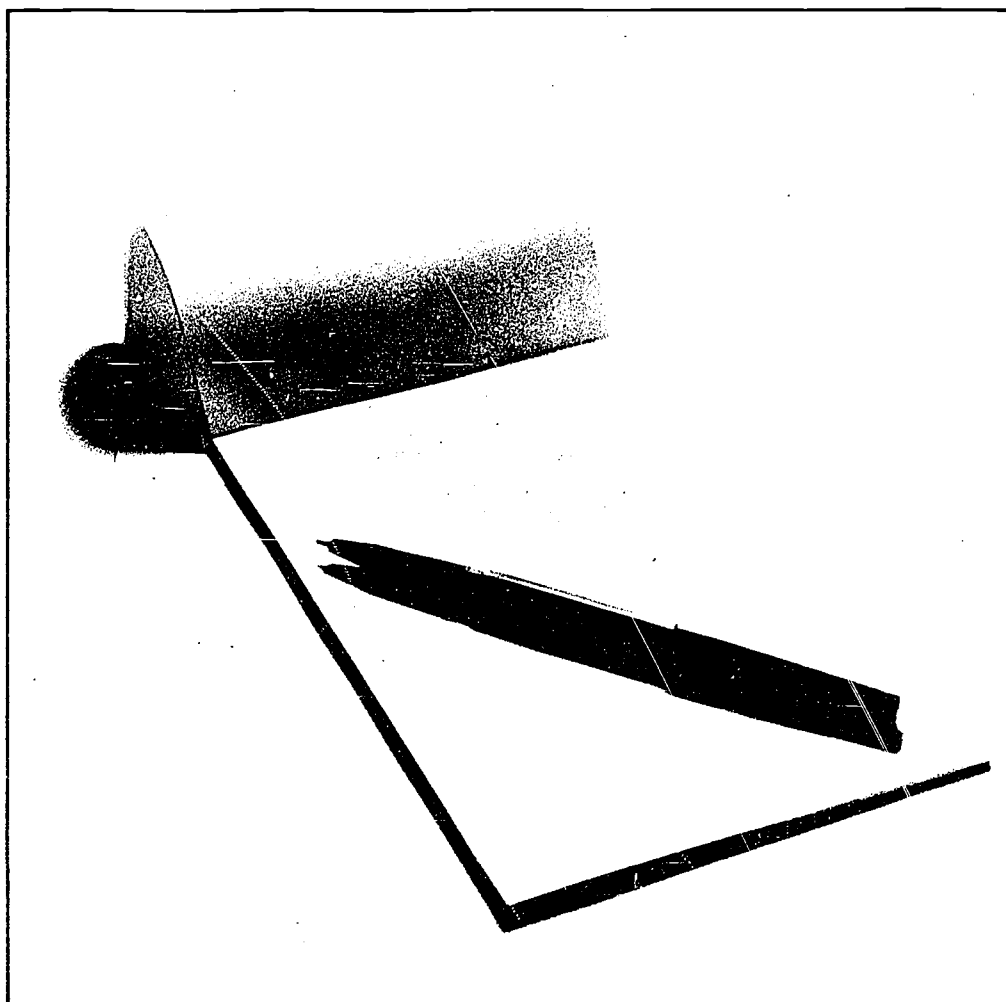
The philosophy of this approach is to use all existing or potentially available services and facilities which are compatible with the basic principles presented in Chapter I, and which meet the *Standards for Residential Facilities for the Mentally Retarded* developed by the Accreditation Council for Facilities for the Mentally Retarded.\*

\*The Accreditation Council is a categorical council within the Joint Commission on Accreditation of Hospitals, 875 North Michigan Avenue, Chicago, Illinois 60611. The Council is co-sponsored by NARC and seven other national organizations.

## Chapter II Summary

- Before planning a group home, find out who needs one and what kind they need.
- There is a variety of options for residential services:
  - Temporary assistance
  - Life Start programs
  - Child Development homes
  - Adolescent Development homes
  - Skills Development programs
  - Vocational Development homes
  - Sheltered Living homes
  - Apartment living
  - Residences for the Elderly
  - Foster homes
  - Nursing homes

### III. Getting Started



### III. Getting Started

The beginning phase of a project always runs the risk of being a "messy" phase in which the goals, direction, strategies and sequence are ill-conceived and poorly understood. For this reason, the planning phase should be carefully designed.

This handbook recommends a sequential approach to the project. While the steps appear to be defined in a recipe fashion, the implementation of these steps is governed by your community's needs and resources.

You will be able to make necessary modifications in this recipe approach if you are alert to the meaning of the information you collect.

#### Developing a Plan

A plan is nothing more than a blueprint of what you intend to do.

Your plan may be a means of publicly announcing the project's goals and the strategies to be used in achieving those goals.

The first phase is a problem definition phase. A committee of the local ARC, an action coalition, preferably including two or three parents, may initiate the project.

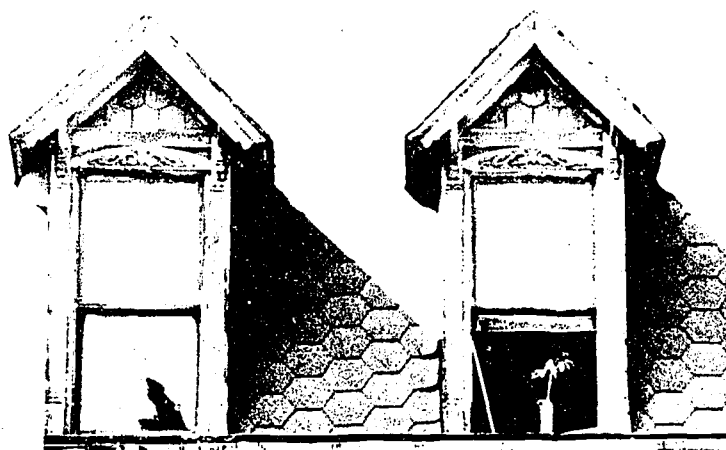
#### Defining the Problem

Talk with a variety of parents and professionals to prepare a basic definition of the problem in your community.

- Collect all available information about the current provision of residential services in your community.
- Determine the various types of program alternatives currently available for community-based residential services.
- Identify the basic problems of the current system.
- If funds will permit, make site visits to view first-hand examples of model facilities in other communities. Try to get local citizens and/or businesses or corporations to underwrite costs of travel to visit these programs. Interview the activists in the communities you visit about the problems they met in order to avoid unexpected hurdles.
- Make a spot survey of the attitudes of the community toward the problem.
  - Do key citizens and officials and parents agree that a problem exists and that improvement is needed?
  - What is the attitude of retarded persons and of their parents toward a possible change in the type of service system?
- Based on the information you have collected, make an initial determination of obvious solutions to the problem.
  - What are you trying to do in this community?
  - What are the long-term consequences of the current system versus the one you propose?
  - Do you need more group homes?
  - Do you need other types of services first?



- Estimate the requirements for completing the next step (Defining the Need) in terms of:
  1. Time;
  2. Money;
  3. Manpower.
- Discuss the approach with key leaders in your organization or central group.
- Prepare a brief report which outlines and qualifies:
  1. Apparent scope of the problem;
  2. Initial thoughts concerning potential avenues for solution;
  3. Objective and scope of the survey (Defining the Need);
  4. Estimated requirements for completing the survey in terms of time, money and manpower;
  5. Recommendations on whether or not to proceed with the project.



## Defining the Need

- *As part of a comprehensive system of community services, a community-based residential facility should be available when it is in the best interest of the individual and his family for him to reside away from his natural home.*

Before considering the development of a planning approach to securing residential services in the community, it is necessary to determine what the needs are for that service. In other words, find out how many mentally retarded people in your community require some type of residential service.

The determination of need may be done in a variety of ways. Some community action groups have conducted extensive census and door-to-door surveys to locate children and adults in their community who need some type of service program. Many have asked all area agencies to contribute to a master list. Others have carefully examined the populations of the state institutions to document the number of persons from the community who legitimately should be returned to community programs. Waiting lists for institutional placement are also valuable sources of information regarding the extent and nature of the need for a residential service.



The information collected to document the need for some sort of residential program should be prepared in such a manner that it clearly demonstrates:

1. Documentation of the total number of individuals who could immediately enter a community-based residential program;
2. The number of individuals estimated to need residential programs now and in the next ten years (this figure is derived by applying the projected incidence figure to the projected community population).
3. A listing of individuals according to age, nature of their handicap and level of retardation.
4. A listing of individuals according to their geographic location within the community.

The development of a strategy to survey the community's need for residential services can be as simple or as complex as you desire. If you anticipate opposition to the project or if the service delivery system of your community is a very complicated system, you will probably need more detailed justification for developing or expanding services.

Basically you are attempting to determine:

1. The number of individuals needing a residential service;
  2. Where these people currently live;
  3. The individual's current level of retardation and other handicaps;
  4. Identification of expected learning needs or program indications.
- Determine the questions to be asked and identify the target groups which are to receive the survey questionnaire. Target groups may include:
    - Parents;
    - Social workers;
    - Educators;
    - Public Health nurses;
    - Physicians;
    - Welfare Agencies.
  - Identify the mechanism you will use to obtain this information:
    - Direct mail;
    - Personal interview;
    - Telephone calls;
    - Combination of all techniques by using the same structured format in each case.

- Prepare the questionnaire and distribute it to parents, placement agencies, public health departments, mental health departments, school systems, welfare agencies, and staff of institutions now in use. Ask these individuals to collect additional information for you by using your questionnaire.
- Secure wide publicity about the survey and encourage parents to contact you for inclusion in the survey.
- Ask that every civic club, church and religious group in the community help with the survey by locating individuals who may need a special service such as residential programs.
- Transfer the survey information to graphs and charts for presentation with your written report.
- Determine the extent to which the problems you discover are affecting other elements of the service delivery system in your community.
- Analyze all of the information and determine what types of residential facilities are needed immediately and how many probably will be needed within the next ten years.

Recognize that a facility developed now may have a different use in a few years. As the number of facilities increases, uses may shift, change and become more specialized. Keep flexibility in mind—in geography, type of house, nearness to transportation, recreation, etc.

- Survey the community's available resources for meeting the identified needs.
  - What are the currently available options for residential programs?
  - What are the potential sources of funding for new or expanded services?
  - What additional community services will be needed to support the residential programs?
- Meet with consultants to interpret the data and to select alternative approaches for solving the problems—both short and long range. Chapter IV discusses the variety of consultants you may wish to contact.
- Prepare a written report containing:
  1. Statement of the reason for undertaking the survey;
  2. Statement of the problem definition;
  3. Summary of survey results;
  4. Outline of individual needs as discovered from the survey results;
  5. Recommended direction to proceed; that is, how to solve the problem.
- Present the report at a meeting of the various community representatives indicated in Chapter IV.
- Secure initial commitment from the group to support the plan and assign people to work groups for developing the formal proposal.
- Publicize the results of the meeting, identifying the organizations and community leaders involved.

## Economics

A special Budget Committee should be developed when you begin this project. The formal proposal should include a fairly accurate budget analysis of the proposed service system.

During the early activities you obviously will not have enough information to make final decisions regarding the type or number of residential facilities to be proposed. You can, however, make a cost analysis of the various options. The final budget organization will then be a simple and rapid task for inclusion in the Proposal.

You will discover that a single guideline for budget development is deceptive in that a unitary approach to budgeting is no more satisfactory than a single approach to program development. Homes for more independent people, out all day in jobs or workshops, will, of course, require less staff than those for non-ambulatory or semi-ambulatory people. Yet, even those most in need of help now will progress toward greater independence and less need for staff.

The budget should reflect an awareness of the program needs, the anticipated progression toward greater independence of many client residents, and the administrative structure of the service.

The OASiS Corporation has developed three separate approaches to a budget analysis based on income, and you will find examples of these on page 76. You may wish to develop similar analyses based upon other factors of your community's needs.

Your budget may or may not take into account the costs of building and furnishing facilities prior to opening them for services. The budget document should, however, specify that these major areas are *not* accounted for, if that is the case.

Many communities have preferred to lease facilities for most residential services in order to avoid the investment of large amounts of capital. Your budget should reflect cost of changes which are demanded by codes, such as new doors, outside steps, ramps, etc.

Your proposal should reflect your awareness that the planning budgets may not account for rent which may be paid by employed adults.

Additional information is available from community leaders, other organizations, the public library, the city accounting department, and other consultants.

The step-by-step manual, written by Robert Elkin and Delroy Cornick, entitled, *Analyzing Costs in a Residential Group Care Facility for Children*, is also recommended to your attention. The manual may be purchased from the Child Welfare League of America, Inc., 67 Irving Place, New York, New York, 10003 (Cost \$3.00).

## Writing the Proposal

After you have completed the collection and analysis of the information specified in this chapter, you are ready to begin compiling your proposal for community-based residential services.

The primary purpose of the proposal is to establish the goals for community services and to recommend a solution to the problems which have been identified.

The secondary purpose of the proposal is to secure a wide base of community support for the project. The involvement of an appropriate cross-section of community organizations, professionals, community leaders, and service agencies will more likely assure community support.

The proposal should receive maximum publicity when it is completed and every agency or group involved should be recognized as contributors, if not co-sponsors, of the project.

The actual mechanics of writing the proposal need not be a difficult nor complicated process. The proposal should be straightforward and easily understood. You may follow any format you choose, providing that it presents the information in a logical and interesting manner.

The first step in preparing your proposal is to decide on the Table of Contents for the document and ascertain that individuals or groups are developing the materials to fill each section of the document.

The following example of a table of contents is one way in which you can organize the information to make it useful:

Title Page

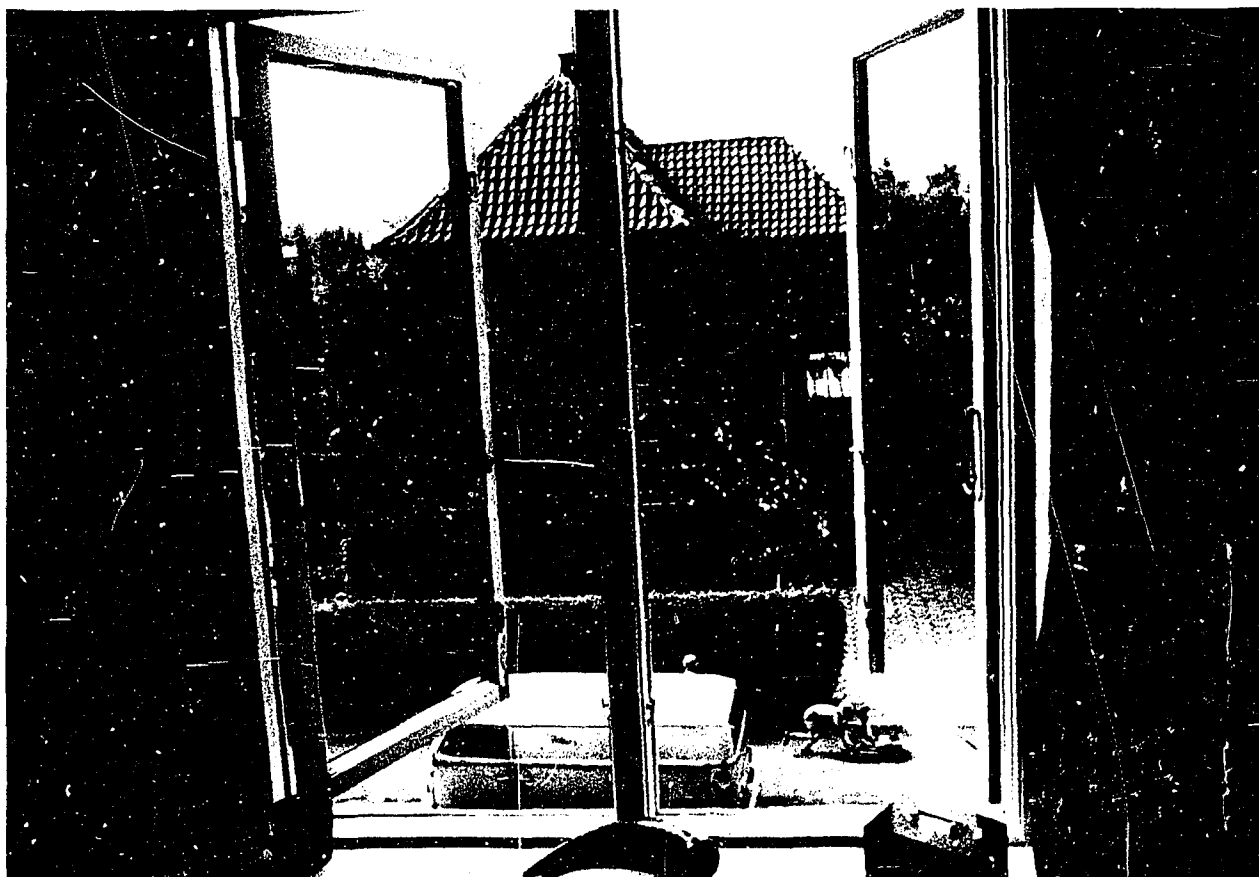
Table of Contents

Foreword

Brief discussion of why the project was undertaken and a prediction of its consequences for the community.

Acknowledgments

Include here the names of all individuals involved in the planning and organization of the project. Be sure to include an alphabetical listing of *all* agencies, organizations, and clubs who are involved. Remember that you are still working to secure commitment to the project.



## Overview of the Plan

This should be a brief summary of the entire proposal. The Overview tells the reader what he is going to read as he continues into the document.

## SECTION I: Philosophy and Guiding Principles

This is one of the most critical sections of the proposal since the guiding principles are rather like a constitution or contract. These are the principles upon which all decisions will be made and by which evaluation of the services will be done. It is essential that you gain group commitment to the principles at the very beginning and publish the fact that "all of these people and these organizations have committed themselves to these basic principles."

### Definitions

It is necessary to define the words and concepts which may have multiple meanings or varied interpretations. For example, "normalization," "group homes," etc., may be interpreted in a variety of ways, and you will, therefore, need to define the way in which you use these words. The glossary on page 72 is recommended as a set of definitions which you can use verbatim in your document. These definitions have resulted from a wide variety of effort and are identical or compatible with those developed by the Accreditation Council for Facilities for the Mentally Retarded.

## SECTION II: Statement of Community Need

In this section you will present the results and analysis of the survey which documents the numbers of people who currently need a residential service. You should also discuss the methods used for determining the need for service.

### Community Resources

Identify and analyze the current availability of supportive services in your community. Briefly show the relationship of these services to the proposed residential service system and justify the relationship on the basis of the Community Services Standards published by the Accreditation Council for Facilities for the Mentally Retarded.

## SECTION III: Proposal for a Comprehensive System of Residential Services

Explain here the various types of residential facilities and services needed in your community for the long-range development of a comprehensive service system. Your specific project proposal may focus upon only one or two types of facilities as a start, but the long-range plan should be made apparent.

## SECTION IV: Planning Budgets for the Various Types of Residential Services

Include here examples of budgets for the wide variety of residential services, but focus specifically upon the planning budgets for the initial development of the one or more services proposed.

### Proposed Sources of Funds for Residential Services

It is important to identify potential sources of funds for supporting the service. You may also wish to note that such homes should pay for themselves with the state supporting each resident from one or another agency and in some cases, ultimately from residents' earnings.

## SECTION V: Program Plan

This concluding section should announce the timetable you have evolved for establishing the first residential facility. Identify the activities in the sequence they will occur over the time-span you have projected. Indicate here the individuals or groups who will play major roles in accomplishing the project's goal.



After the proposal has been organized and written into a sequence which makes it a public declaration of intent, you are ready to get approval from your advisors, Board of Directors, or groups responsible for the project. If the initial steps are followed in preparing the information for the proposal, there should be no difficulty in assuring approval.

At this point you should print enough copies of the proposal to allow for wide distribution. Check with businesses, churches, or other organizations to find an inexpensive or free method for reproducing copies.

A local printing company may be persuaded to print the copies free if you furnish them with "camera-ready" typed pages for an inexpensive photo-offset printing method.

Type the proposal on regular 8½ x 11 inch white paper (do not use legal sized paper) and allow a sufficiently wide left margin for staples or binding.

## Presenting the Plan

As you prepare to present materials to citizen groups and the public at large, there are some materials available which can help you in explaining to them the basic concepts behind community-based residential services. Two slide-tape productions are available from the offices of the National Association for Retarded Citizens, designed to augment the public information aspect of this guidelines handbook. The titles of these two presentations are, *Where Do They Go From Here?*, which deals with the normalization principle and outlines the basic philosophy of community-based services. The second show, entitled *Are They Happy?*, discusses the developmental model. These two concepts, normalization and the developmental model, go hand-in-hand and the media presentations can be used in a wide variety of ways. They consist of 80 color slides, an audio-tape sound track with text and music, and an accompanying projectionist's script, which makes it simple to synchronize the visuals with the sound track during presentation. For information concerning these presentations, write to:

Program Services Department, National Association for Retarded Citizens, P.O. Box 6109, Arlington, Texas 76011.

Copies of the proposal should, of course, go to every organization, club, agency or individual involved in its development. Through wide dispersal of the document, you serve an essential public education purpose, and you also employ an excellent strategy for developing support for the later phases of the project.

The Public Education phase of the project will be discussed in Chapter Five, but it is important to note at this point that the early dissemination of the proposal to a wide audience lays the groundwork for influencing the public to support your effort.

People generally are influenced by the considered opinions of public agencies and community leaders; therefore, it is important that the general public become aware of the broad base of input for the proposal and of the fact that it is endorsed by people they respect.



### Chapter III Summary

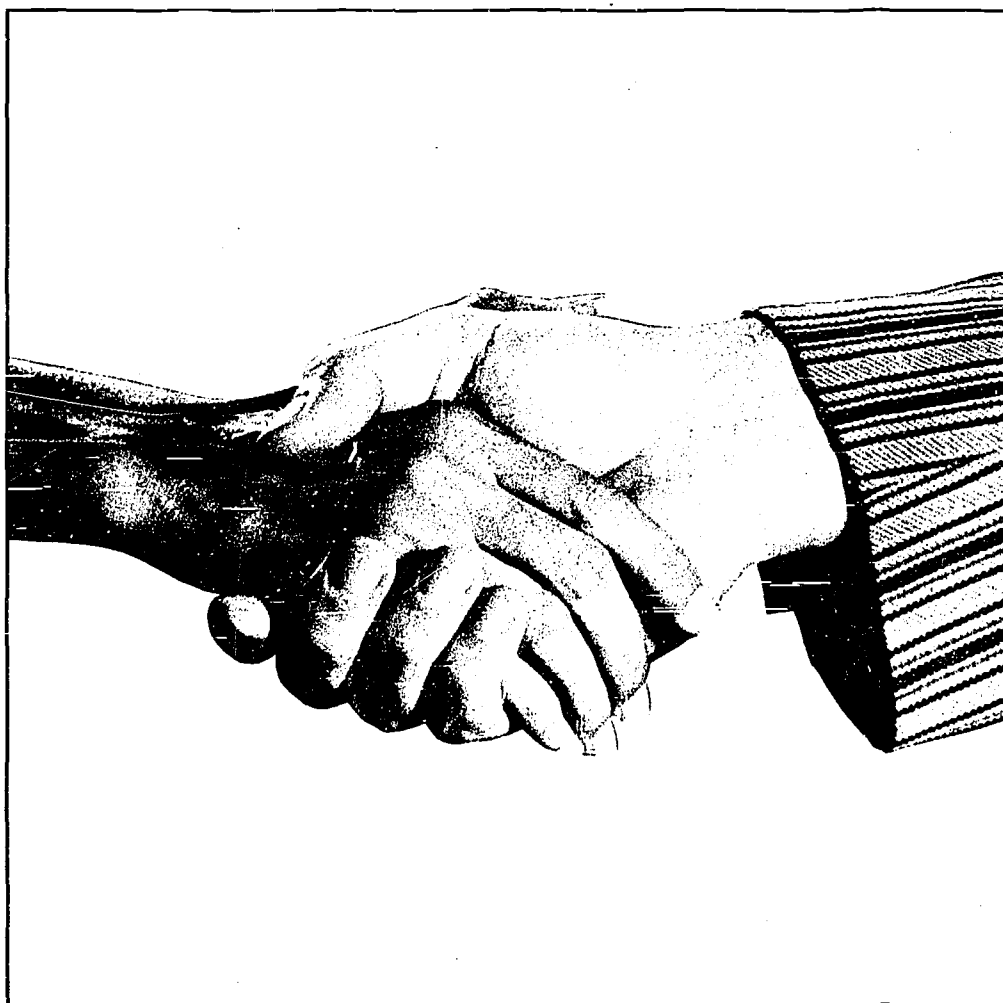
- The initial plan is your blueprint of how the project should proceed.
- Define the problem of service options by collecting information about every aspect of the problem and logically presenting the community needs as they relate to the problem.
- A survey of community needs serves a public education purpose in addition to providing justification for your project.
- Budget planning should reflect an awareness of program needs, the progression toward greater independence of many residents, and the administrative structure of the service.
- The formal proposal publicly announces the goals for community services and recommends a solution to the identified problems.

#### Check List

- Identify consultants, advisors and workers.
- Host a meeting to structure the project.
- Adopt a set of guiding principles.
- Develop a work committee to survey the community needs.
- Develop a survey technique and procedure.
- Conduct the survey.
- Analyze and compile the information.
- Develop a work committee to survey community resources.
- Compile and analyze the information on resources.
- Identify the types of residential service options.
- Host a meeting to review the information and to develop goals.
- Develop a committee to prepare a planning budget.
- Organize all materials into a proposal.
- Print and distribute the proposal.



## IV. Getting Help



## IV. Getting Help

Any successful community effort necessarily involves many different people who represent a wide variety of interests, concerns and abilities. While community involvement should not be limited to them, it is obviously necessary to include a variety of community leaders in your planning from the very start.

To be totally realistic you should be aware that you will probably face opposition from a number of sources. Some leaders and parents seem to go out of their way to dream up hurdles and barriers to projects of this type. For this reason some community groups have given less attention to gaining public support and just moved ahead with opening a program.

Community leaders usually make supporting or opposing decisions according to:

- Their personal value system;
- The information available to them and their understanding of that information;
- The opinions of people whom they respect; and
- The projected effects of their decision upon other projects and priorities.

You and your group *can* influence each of the above decision factors in a constructive way to achieve an improved service delivery system for the mentally retarded citizens of your community.

*Professionals* in your city have very specific interests in the various elements of a service delivery system. You can speak to professionals about those interests in an effort to elicit their assistance and good will.

Contact local chapters of various professional associations and ask for their help in studying the community's needs and in formulating a plan to meet those needs.

*Social Workers* have special interests in the total services available, and they will be very helpful in the collection of information for your proposal.

Contact the local or state chapter of the National Association of Social Workers and ask for their advice and planning assistance. If you cannot locate the local chapter, call the social worker at a local public health department or public welfare office and explain your interest in securing social work input.

*Educators* have a major role to play in the success of a residential service system. At specific points in your project you will need the advice and assistance of educational consultants for program development. Someone from the administrative level for public education should also be contacted early to assure his understanding of the project and his cooperation in securing necessary information for planning.

*Physicians* should be involved early in the planning phase since they will ultimately have responsibility for the health care programs of a residential service. One must also be alert to the physician's potential leadership role in the community.

Experience indicates that if two or three public-minded physicians actively support the project, it moves more rapidly toward completion.

*Public Health Nurses* can serve a vital function in all phases of the project. Nurses will, in many ways, serve as an ongoing link with the low income population of the community which is usually less vocal about the need for services.

Contact the local Nursing Association and the director of Public Health Nursing in your community. Arrange for them to have some sort of official representation on your committees as you do with other professional groups.



*Vocational Rehabilitation* specialists will be able to contribute much to the project, especially in terms of long-range planning for the use of community resources in program development.

The vocational rehabilitation expert should be able to serve as a connecting link with many other elements of the service system, particularly as it relates to adults.

*Other Professionals* in the community should be contacted for their special areas of knowledge and leadership. For example, it can be very helpful to have the commitment and active involvement of an expert from the city's department of Urban Planning.

There are many knowledgeable and helpful people associated with city and county government who should be urged to participate in the early planning of your project. Someone from the legal department, the department of recreation, the department of transportation, the department of budget, or other departments may be contacted as you see the need arise.

Local industry may employ experts who could provide needed help, and these companies are often willing to lend these experts to assist in worthwhile community projects.

### Community Groups

While you may have already secured agency involvement through the selection of professionals, it is always wise to establish an *official* link with the community agencies which relate to your project.



The local chapter of the National Association of Real Estate Boards should be contacted, since the members of this group will be able to provide help in the planning and location of the residential facilities. Special effort may be necessary to teach realtors the benefits of group homes to a community if they fear effects on property values.

Civic organizations should be kept regularly informed of your project activities. A civic club will occasionally wish to co-sponsor a project of this type or their members may wish to donate time and energy to solve the variety of problems which will arise as the project proceeds. Organizations such as Civitans, Junior Club Women of the General Federation of Women's Clubs, and Jaycees have been involved in many communities.

Special interest organizations similar to Associations for Retarded Children should also be involved. The local units of United Cerebral Palsy Associations, Associations for Children with Learning Disabilities, Associations for Autistic Children, the Epilepsy Foundation, and the Coordinating Council for Handicapped Children, can all be expected to share an interest in developing a high quality service system.

### Governmental Agencies

During the later phases of your project things will move more smoothly if you have involved the various governmental agencies in your planning phase.

Those agencies concerned with the public health and welfare can be expected to offer a variety of insights and assistance to your project. These agencies, like all others, need to be sold on the necessity of the project and every effort should be made to secure the agency's commitment and cooperation.

Contact officials in the city department of zoning, the fire-safety inspector and the public health inspector to avoid any last minute surprises as the project develops. Get the information without raising needless fears and hurdles. You may find current codes and restrictions so unsatisfactory and damaging to the intent of your project that you will seek changes in the ordinances, but you should know what you will be facing.

Find out which code terminology is least restrictive in your community. Many groups find that "Boarding House" is the least restrictive label. Never use "Institution" as a label, since it calls into play different codes with difficult, inappropriate and expensive hurdles.

The city or county Mental Health and Mental Retardation Centers have a direct and immediate concern for improving the service system. Although your project may choose to be a privately controlled program, you cannot overlook the planning and direction available from the Mental Retardation Center. Ideally, your project will receive the full endorsement and assistance of the county Mental Retardation Center. It may duplicate or overlap others being planned; early questioning and coordination may save resources.

A cardinal point to remember is that involvement of governmental agencies does not mean relinquishing control to those agencies. Your friendly relationship with parts of a bureaucracy should not be allowed to control the project's goals or the direction of its effort.

### **Labor and Trade Unions**

The labor and trade unions are very powerful groups in many communities and their commitment to your project will provide many benefits. It is widely known that the trade unions often exert great influence over changes, or modified interpretations, of local ordinances and construction codes.

In addition to the valuable assistance these groups can provide in planning construction or remodeling, they may also provide a cadre of volunteers and advocates for later stages of program development.

### **How to Accept and Use Help**

To ensure the development of community-based residential services and to ensure their stability as ongoing elements of the total service delivery system, a broad base of community support is necessary.

Choose professional consultants and business leaders carefully. Keep the ultimate goal always in mind. Involve people who can and will exert genuine effort to achieve the project goals.

Recognize that many people in the community will give their moral support to the project but have no time nor motivation to become active workers. These people are important to you. Give them public recognition whenever possible.

Encourage the professionals who are "doers" to take leadership roles in the project. Keep the "non-doers" in an advisory capacity.

Encourage non-professionals to assume responsibility in designing strategies and chairing meetings.

Continually encourage everyone to maintain a focus on the needs of the handicapped child or adult. Avoid serious compromise of your project by not allowing obstacles and bureaucracies to distract the group from the real issue at hand — providing good services.

People want to feel useful and constructive. Be generous with your gratitude and lavish with your praise — anyone who helps, even in the smallest way, is your friend.

As the project gets underway, some key member of your group should initiate a continuous publicity campaign. Give as much public recognition as you can achieve to those individuals and groups involved in the project.



## Chapter IV Summary

- Any successful community effort necessarily involves many different people who represent a wide variety of interests, concerns and abilities.
- Professional consultants should be chosen for their knowledge of the problem and potential solutions to that problem.
- It is wise to establish cooperative liaison with the community agencies which relate to your project.
- Gain an early understanding of the various codes and ordinances which may affect your project.
- Public recognition of those who help you should be generous—anyone who helps is a friend.

### Check List:

- Enlist support from community leaders, professionals, community groups, governmental agencies, labor and trade unions.
- Choose professional consultants and business leaders carefully.
- Initiate publicity campaign.

## V. Laying The Groundwork





## V. Laying The Groundwork

The weapon is information. The trump card is knowing more about the social problem than the forces of inertia.

Robert Buckout,  
*Toward Social Change*,  
1971

It is a great advantage to the success of your project to have wide public support. The involvement of various community groups and clubs becomes especially important as your project becomes more active.

This chapter is devoted to the public education strategy which is necessary for the achievement of your immediate and long-range goals.

### Developing Strategy

There are two basic reasons for developing strategies for implementing your project:

1. An organized effort with clearly identified steps will work best. Without strategy planning, you are subject to all manner of surprises, unexpected hurdles, blocks, doors and negativism with the possible compromise of your plans.
2. Strategies should account for potential opposition from government and/or private bureaucracies. When opposition appears, you should be prepared to take a constructive but offensive stance since a defensive position puts your project at a distinct disadvantage.





The following is excerpted from HOW TO ORGANIZE AN EFFECTIVE PARENT GROUP & MOVE BUREAUCRACIES, by Charlette Des Jardines.

There are public servants who are sincerely devoted to handicapped children, who are making a major effort on their behalf—and who find themselves continuously frustrated by the bureaucracy employing them.

But there are many more who simply fall in with the bureaucracy's slow motion ways, its rigid adherence to the status quo, its resistance to new ideas and new ways of doing things. How many children get hurt in the process doesn't seem to concern them. These are the bureaucrats we are speaking of in this chapter.

To move bureaucracies you must constantly bear in mind that bureaucrats are public servants: that they are paid by you to provide services to you and your child; that you are the master, they are the servants—not the other way around.

Parents who keep this in mind—and act accordingly—usually get action.

Parents who let themselves be intimidated and assume the role of servant to the bureaucrat's role of master usually wind up being treated like a servant. They often end up feeling guilty for having "bothered" the bureaucrat with their problems, for having taken up his valuable time, for having caused him work, etc. . .

You must remember that this is exactly what the bureaucrat is being paid for—and that you are paying his salary.

#### To Move A Bureaucracy

1. You must stop feeling guilty and insignificant.
2. You must stop apologizing for asking a bureaucrat to do a job you are paying him to do through your taxes.
3. You must stop begging for what you are entitled to by law.
4. You must not be patient. No matter how often you are told to, "Please be patient, we are doing everything we can," remember that patience has never moved a bureaucracy. Only impatience has ever made a bureaucracy move.
5. You must not accept those old excuses: "There isn't any money;" "We need more time;" "We've made a lot of progress;" etc. . .
  - a. There is never going to be any money unless you demand it.
  - b. Be miserly with the time you give a bureaucracy to get a job done. It is a natural law of bureaucracies that the more time you give them, the more time they will take—and often still not get the job done.
  - c. If there is still a single handicapped child left unserved, the "progress" is not good enough.
6. You must stop whispering while everyone else is shouting. You can win battles, no matter how small your parent group, if you make enough noise.
7. You must not be afraid to offend bureaucracies. Do not be afraid to complain: To their superiors, your legislators, the mayor, your alderman, the governor, the newspapers, radio, television, and other press media.

Do not be afraid to expose incompetence, inefficiency, dishonesty, stealing, bribery, or any other wrong-doing, no matter how powerful the guilty one.
8. Your child's welfare should be your primary motivating force, not the welfare of bureaucrats.
9. You must get rid of the attitude that "You can't fight City Hall," "Nothing can be done," etc. . . You must believe there is a good chance your problem will be resolved if you are persistent enough to see the problem through.
10. You must use mass action. Remember that politicians are dependent on your vote and those of other parents, that all government officials are dependent on public support. This is why organized groups who make noise are so effective.

The people for whom we are advocates cannot always speak for themselves. Therefore, we must speak twice as loud.

- Prepare a list of the various community groups and organizations who may, for whatever reason, offer some sort of opposition to your project.
- Seek out opportunities to speak with these groups and to present the whole picture of the service system and how the community as a whole will benefit.
- Host a special meeting to plan strategy for the public education campaign. Call upon experts available in university departments of communications, radio and television, newspaper writers, and publicity agencies to contribute their good advice.
- Outline the elements of a good campaign to teach the public the facts about needed services, what's involved, and how the average citizen will benefit as a member of the community.
- The campaign will probably entail some costs and you should plan early to raise enough money to finance a successful public education effort.
- There are three specific groups to whom you will need to direct special effort:
  - Parents;
  - Existing institutions;
  - Placement agencies.

Poorly informed parents can become quite fearful and alarmed if someone tells them that this new plan will result in their child "being thrown into a hostile community with no protection," or that "if the child leaves the institution, the parents will never be certain that he will have a secure future."

A number of common fears emerge on a consistent basis, and you should be ready to respond to them. Knowledge and its application to the question should be enough to resolve the fears. Some of these common concerns are given here:

- "Some retarded individuals will never be able to live in the community and it is damaging to create this expectancy."

Like many fears, this is an example of two issues being tangled together. While it is true that many persons may not be able to function independently in the community, it is not true that high expectations are damaging. If we don't raise our expectations, we will never improve our programs.

A major point to remember is that, while some individuals may not live *independently*, they can still live in the community.

- "Parents have no assurance that their children will be properly protected in small group homes."

There are many ways to assure that programs are properly supervised and monitored. In reality, the problems found in most institutions result from too many residents in one place. Proper supervision and ease of monitoring is more assured in small facilities even if they are dispersed.

The questions of supervision and quality of programs are critical and these details should be worked out early in the project.

Some parents fear that the community-based programs lack longevity and security. One should point out that if the program is publicly supported it is as "secure" as the institution.

- "Parents become perpetually responsible for their child if he is moved into a small group home."

One of the advantages of the community-based system is that it permits as much or as little parent involvement as parents wish. In reality, there are many parents who simply cannot cope with the continuous responsibility for a severely handicapped child or adult. While the group home system should encourage consistent parent involvement, it should also be prepared to accept those who choose not to be involved.

The protective services and long-range planning should be designed to afford more individual awareness than was ever possible in large residential settings.

- "If parents accept the new group homes program, it means turning their back on the institution after working so hard to improve it."

You cannot afford to turn your back on any part of the service delivery system. Through dispersal into group homes, the institution can reduce its population to a more realistic size and then provide truly outstanding programs for those who need that particular type of program at that period of their lives.

It is unfortunate that people have been led to fear that one type of service will destroy the other. We are working to assure quality programs and a genuine access to developmental opportunities for everyone. The argument should not be destructive since we are trying to build and evolve services, not destroy them.

Any time you encounter arguments which are designed to create fear and anxiety among parents, you must act swiftly to correct the situation.

The existing institutions should become active participants in your project and assume their legitimate role as only one option within the service system. Getting institutions to accept this role may require considerable pressure, but your cause is just and with sufficient public support, the institutions will join in the effort.

The community agencies which frequently seek residential placement for children and adults can generally be expected to endorse your project more readily than the larger bureaucracies which operate more remotely from the public. However, you cannot depend upon this support—you must assure it by involving the agency in the project from the very beginning.

When you need to communicate information to a public group from which you expect action in return, you should use the simplest, cheapest, most direct means of communication which is sure to reach that target audience. The most elaborate and expensive means of communication are worthless if they do not reach the target audience.

The cheapest and quickest means of communication are completely adequate if they do reach that audience and the audience understands the message which they convey.

Among media of communication which you should consider for any public information campaign should be the following, arranged in approximate increasing order of expense:

– Ditto	– Newspaper Advertisement
– Mimeograph	– Audio-Tape
– Multilith	– Radio Spot
– Print	– Slides
Bulletin	– TV Spots
Brochure	Slide-Tape
Book	Film
– Poster	Video-Tape
– Billboard	– Media Show
– Bumper Sticker	– TV Production
– Decal	– Film

Each of these media has a particular character, and is useful for conveying certain kinds of messages. A ditto is more informal and seems to be more swiftly done than a mimeo sheet. It is not a good argument to say, "We have a ditto machine; therefore, it is more efficient for us to use ditto than to go elsewhere for mimeo." A ditto which fails to communicate the desired information to the target audience, and does not elicit the desired response from that audience, is wasted time and money. At times the impromptu quality of a ditto message is perfect for the target audience, such as late-breaking news distributed to a meeting, messages attached to classroom doors, hand-outs distributed to a neighborhood to announce a suddenly called meeting. However, the more formal quality of mimeo, or even multilith with its increasing expense, may be the necessary medium for a formal presentation of a residential services plan to a PTA meeting or a City Council.

You should use the simplest and least expensive means of communication which can successfully communicate the message to the target audience.

Study the situation very carefully. You know your community, and you know which community leaders will be able to muster the support necessary for completion of your plan. Define that target audience very precisely. Think about what actually reaches you in the press, on the radio, on television. What moves you to action?

In defining your target audience consider their age or range of ages, their economic level, their social status, the kind of vocabulary which they use commonly, their background in this subject matter, their preconceptions and perhaps their prejudices. Think carefully about the person you are trying to reach. What kind of appeal will influence that person?

Before you ever attempt a public information campaign, define in precise terms the

specific action which you desire from the target audience. Never extend a general appeal asking them to "support us in our cause." Tell them what they can do. Give them an address to which they can send money. Give them a telephone number which they can call to volunteer their help. Give them the date, hour, and place of a meeting which they can attend. If you do not provide concrete check points of this kind, you have no way of knowing if your general public information campaign is having any effect. You can't afford to hope for the best and wait for election day.

In attempting to decide exactly what to communicate, each member of the planning group should write in brief, telegram form, everything which he or she *knows*, *believes*, or *feels* about the project. If possible, these should be listed separately. In any given campaign it is quite likely that the things you *know* would be strongest fiscal arguments, but the things you *feel* will be basis of the persuasion.

All of these brief telegraphic comments should be arranged in alphabetical order and typed for reconsideration by the planning group. Each person involved in the public information campaign, and perhaps others involved in your project, should rank order the entries in descending order of significance by placing the number (1) along-side the item deemed most significant, (2) by the next most significant, etc. Add the scores attached to each item and rearrange the entries in descending order of significance with the most important items at the top. Discuss this priority list carefully with your group before attempting a communication program. After full discussion, retain the top five or six items and work with these specifically in trying to persuade the public. It is critical that you focus upon the most important aspects of your project, the ones most beneficial to your community, and the ones which will be most persuasive with your selected target audience. After you have determined these priorities, trust your consensus and get to work on presenting that information to the people who need to know about it.

Get to know the public service directors of your local broadcasting stations. Explain to them what you are trying to do, ask them for their assistance, and be sure that you give them all of your publicity materials in exactly the form which is most useful to the public service director. Expect them to help you, but don't ever expect them to do your work for you.

Basic guidelines on public information are available from a number of sources, including the National Association for Retarded Citizens.

- If you need detailed assistance in preparing press releases, news articles, radio spots, etc., secure a copy of *FINE POINTS OF PUBLICITY* (25 cents) from National Association for Retarded Citizens, P.O. Box 6109, Arlington, Texas 76011, and use it to guide your campaign.
- Send regular press releases to all local newspapers at every stage of the project.
- Convince the editors of local newspapers and television stations to prepare a feature story about the project.
- Every radio and television station has a number of talk shows which deal with current issues and problems. These present an unusual opportunity for you to tell the public about the project.
- Secure a copy of *HOW TO ORGANIZE AN EFFECTIVE PARENT GROUP & MOVE BUREAUCRACIES* (\$1.50), from the Co-ordinating Council for Handicapped Children, 407 South Dearborn, Room 950, Chicago, Illinois 60615.





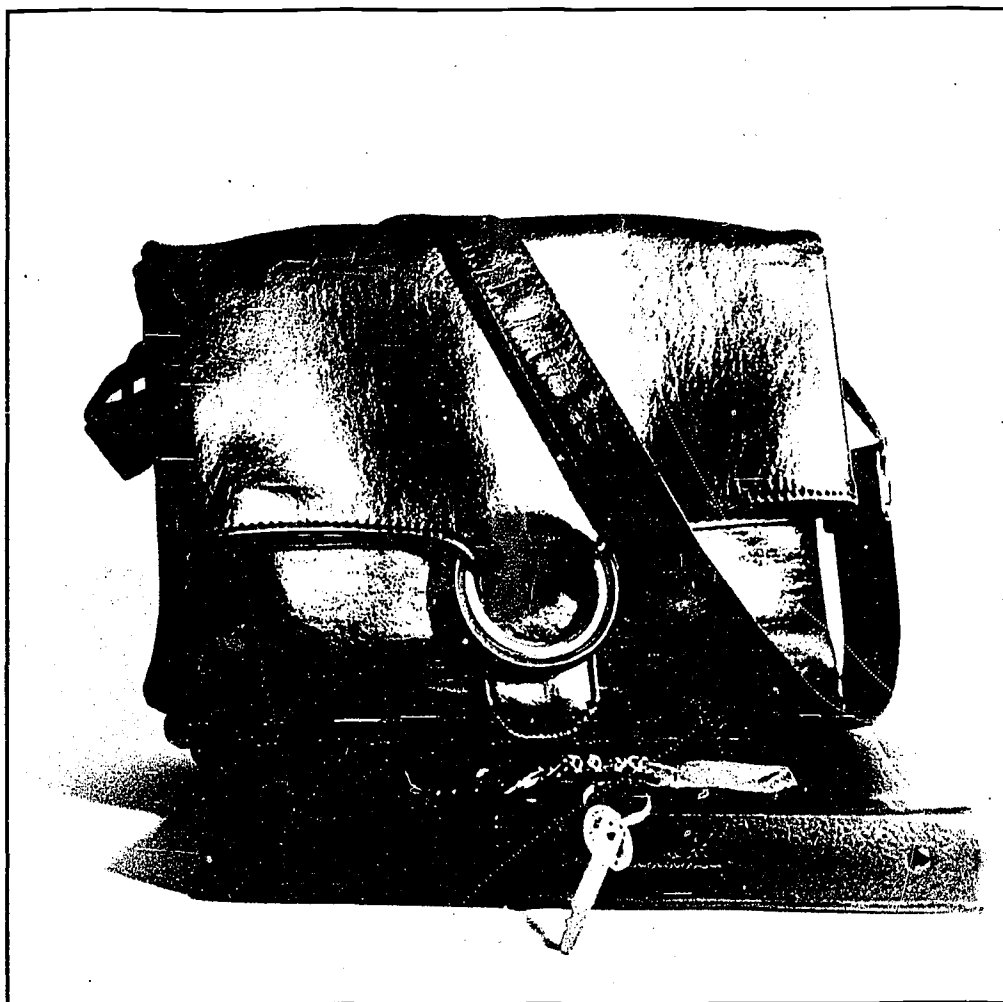
## Chapter V Summary

- A good public education program will smooth out many rough spots as you implement your project.
- To move bureaucracies you must bear in mind that bureaucrats are public servants; they are paid by you to provide services to you and your child.
- When you tell the public about your project and expect them to take some action, you must be specific about what that action is to be.
- By defining your target audience you can successfully communicate your message.

### Check List:

- Develop public education strategy.
- Define target audience.
- Decide exactly what to communicate.
- Use simplest, cheapest, most direct means of communication to reach target audience.

## VI. Getting What Is Needed





## VI. Getting What Is Needed

One key issue in attempting to secure community-based residential services is the legality of the plan being proposed. You may analyze your community needs, survey available resources, develop a coordinated plan for securing services, and find quite unexpectedly that the kinds of services you desire are illegal. This may be a result of zoning, of fire ordinances, or a multitude of other factors.

You may even find that enabling legislation under which revisions of existing codes could be made does not exist. This requires that you secure sponsorship of a bill which will pass into law provisions for the kind of facilities you desire.

This is a complex, difficult, and time-consuming process, but necessary if enabling legislation does not exist. These *Guidelines* will not attempt even a brief outline of all the possible variations which exist from state to state in the legislative strategy. However, there are certain basic principles which do apply to the legislative strategy in any situation. The Governmental Affairs Committee of the local and state Associations for Retarded Children should be contacted as a first step.

It is often necessary to raise funds not only for public information but for the simple tasks of duplicating printed materials, mailing letters requesting support, a telephone budget, etc. One member of the planning group should be assigned the responsibility of organizing and conducting at least a modest fund-raising campaign.

The people involved in the planning group should organize themselves into three task groups. These task groups should define their goals clearly and move vigorously and promptly to complete them. Group A should undertake the responsibility of:

- a. Drafting the proposal;
- b. Finding a sponsor for it in the Legislature;
- c. Planning the strategy for its presentation, support, and implementation.

Group B, in the meantime, should contact a variety of civic organizations and arrange for meetings at which the content and implications of the plan can be presented and discussed. Group C should provide the press with information concerning the impending bill, and should keep continual track of the bill's progress through the Legislature, informing the press of any change in status immediately.

Group A should cooperate with the sponsor of the bill to contact other legislators and other members of the appropriate committees, indicating their interest in, and support of, the bill. At the proper time, which will vary from situation to situation the organizations already reached by Group B should contact legislators corporately and individually, expressing their support of the proposed plan. The kinds of support and influence brought to bear on senate committees and on the Legislature as a whole have been widely documented and generally understood by most groups successful in seeking social change.

Legislators are representatives of the people, and it is their solemn duty to serve the people to the best of their ability. It is important that they should understand what the people want, and by writing letters, making telephone calls, and through personal visits, "the people" supporting your plan can best serve you by exerting their influence in the democratic implementation of social change.

After the extended committee work necessary for the passage of any bill, a compromise bill will probably result between the House and the Senate.

If this bill is approved at the close of the tedious and demanding process which has been treated in so few lines in this handbook, the bill goes to the Governor for his signature.

If the bill is *not* approved, you have reached another of the potential impasses in the process of change. This will require reorganization, reconsideration, possible redefinition of need and development of a new plan, and, above all, continued dedication and ingenuity.

If the bill is approved and goes to the Governor, he may or may not sign it into law. If he does sign the bill, it then could be implemented through agencies which already exist or through new enabling agencies created by the bill. Your job of bringing the plan into existence continues in a fairly predictable order.

If the Governor vetoes the bill, again you have reached a stumbling block, and you must consider what alternatives are available to you.

In most instances the new legislation will specify one or more state agencies which are charged with the responsibility for carrying out the intent of the legislation. You must then be sure that your project is well understood and endorsed by these agencies. If this approach takes a strong educational effort, your energies will be well spent in securing the agency's commitment.



### Source of Funding

Since there is an obvious relationship between management control and source of funding, you will need to explore the possible variations available to your community.

The availability of federal funds is not considered as a stable source for operation since experience indicates that the presence of federal funding tends to prevent or decrease the development of local and state resources to ensure the continuity and autonomy of the service.

An exception to the pursuit of federal resources may be seen during the establishment phase of the service. The use of federal funds for construction or the use of low-interest, long-term loans through agencies such as The Office of Housing and Urban Development, can be beneficial without compromising the development of long-term resources for operation.

There are basically three sources of funding for community-based residential services:

1. Private funds;
2. Social Services programs such as aid to the disabled, the dependent or the aging, and Medicaid;
3. State appropriated funds through Mental Health and Mental Retardation programs, Public Welfare departments, Regional Centers, etc. . .

In the first two sources of funding, the sponsor (agency or corporation) usually maintains control since these funds are either paid directly to the sponsor or paid to the individual residents, who then pay a proportionate share of the expenses.

The state's appropriated funds to special departments within state government present a rather different problem regarding management control. Depending upon the state, these government agencies may demand full or partial control depending upon the type and amount of funds provided.

The establishment of provisions whereby the state can contract for services is one obvious solution to the dilemma of funding and control.

The Developmental Disabilities Planning and Advisory Councils of some states have taken a different approach to resolve the funding and control dilemma. The Ohio Council, for example, has proposed a system of residential services funded by the State, but controlled by decentralized citizen boards.

There are several strategies you may wish to consider to assure that the community-based residential service system will remain alert to individual needs and become economically stable for long-term operation. Examples may include the following:

- Develop new legislation to provide state funds for contracted services.
- Secure new regulations governing the current utilization of state funds to provide for contracted services.
- Expand existing legislation to provide direct payments, via social services programs, to the individual who then purchases the service himself.
- Develop new legislation to provide state funds to the county, which, in turn, contracts for services or provides them under local control.

While it is not possible to identify all of the sources for funding, some general comments may help as you think through the possibilities in your community. The administration of monies is obviously different in each state and each community. You will need to explore the potential strategies for getting funds on a local basis.

In addition to a pursuit of possible federal funds, examine the use of Developmental Disabilities Act monies. These funds are controlled by state and local governments. At the state level, don't overlook possible funds from Vocational Rehabilitation and welfare agencies.

The California Association for the Retarded\* has prepared a useful manual entitled *Suggested Sources of Support for Community Programs for the Mentally Retarded*. You may wish to secure a copy and prepare a similar guide to resources within your own state.

\*The California Association for the Retarded, 1125 Eighth Street, Suite 312, Sacramento, California 95814. *Suggested Sources of Support for Community Programs for the Mentally Retarded* \$4.25 per copy.

You may wish to explore relationships with the local United Fund Agency. You should also consider special fund raising projects. Local civic and philanthropic organizations represent a great resource since they already sponsor projects like yours in some cities.

A fund drive can also be a most effective technique for acquainting the public with your project. In order to raise funds you must have an issue to sell. In selling your project, you inform the public about the problem and the solution to the problem.

If you have no experience with fund raising drives, the book by Howard R. Mirkin, titled, *The Complete Fund Raising Guide*, is a reference which may help you conduct a successful drive. The book is available from Public Service Materials Center, 104 East 40th Street, New York, New York 10016.

### Location

The location for a residential facility is chosen according to the needs of the resident clients to be served. To allow other factors, such as free land, low rent or donated space, to dominate the location decision is not in keeping with the primary purpose of the service—meeting individual learning needs.

- The location of a facility is based upon the consideration of "what type environment will be most conducive to the development of the residents of that particular facility?"

Review the types of facilities discussed in Chapter II and the principles governing services, then ask these questions about any potential location.

- Can the community setting provide the necessary experiences to increase the independent functioning of each resident?

Residents need the opportunity to move about within the community and to experience a sequential increase in the number and type of activities which demand greater autonomy in decision-making skills.

The area should provide opportunities to utilize a variety of other public centers for shopping, entertainment, and recreation. Keep in mind that the reason for providing access to these opportunities is to help the individual learn to make the day-to-day decisions which are essential to his increasing independence.

Once he has learned to make the decisions he should have a continuing opportunity to practice this skill.

- Does the community setting provide the opportunity for resident clients to experience the security of a home within a normal social context?

The developing child or adult needs frequent and diverse opportunities to interact with non-retarded children and adults. Appropriate social behavior is not developed in isolation.

The developing individual needs a sense of belonging, of being valued as an individual, and being able to exert an appropriate influence on his home environment.

The facility's appearance should be compatible as one of the homes in the community. The physical structure should not isolate nor in any way increase the social distance between resident clients and other residents of the neighborhood. For example, high fences, signs and large parking lots are signals that "this is not a real home" but is more like a small institution.

- Does the community setting have easy and regular access to public transportation?

As the individual expands his world of interaction, he needs to learn how to move throughout the larger community.

As the individual gains greater autonomy, he needs the opportunity to test his decision-making abilities by increasingly independent function, such as traveling alone.

Staff and visitors need easy access to the facility to enhance their conceptualization of the service as a normal learning experience, and to see their roles as social models for the resident clients.

## Restrictive Codes

Many groups who developed community-based residential services report that the problems surrounding licensing requirements, zoning regulations and fire safety codes have proven to be the biggest "headaches" of the whole process.

It is in the area of restrictive codes that you may first encounter the slow motion bureaucracy and the intransigent bureaucrat who appears incapable of understanding the problem.

Be prepared to deal with these problems from an aggressive, well-informed stance. Review the discussion on page "How To Move Bureaucracies."

- Determine which state agency has the authority to license community residences under the laws of your state.

You may discover that there are a variety of licensing authorities which may have overlapping interests in the community residence.

- Examine the criteria and restrictive provisions associated with each type of facility licensed by the various agencies. You may be able to choose which "license label" you wish to be applied to the community residence.

Choose a licensing provision which does not impose restrictions which are destructive to the learning needs of the resident clients.

- The "licensing label" will often determine the zoning ordinance requirements. Inappropriate zoning regulations must be challenged.

Watch the terminology of codes. "Boarding home" is usually a more appropriate label than "institution" or "nursing home." Find out which label is best before making an official application.

Restrictions which preclude an atmosphere conducive to normalized living should not be accepted as final decisions. The successful implementation of a truly developmental environment demands that you avoid compromises in meeting the learning needs of the resident clients.

The future of the children and adults served by the facility is worth fighting for.

- Existing fire safety codes may have to be challenged and changed if they impose an inappropriate burden on the learning needs of resident clients.

Remember that these restrictive codes were designed to protect people, not to enslave



them. Codes are only expressions of what people understood at the time the codes were written. As technology and human needs are better understood, the codes should be altered to reflect these newer understandings.

- If the regulatory agencies become "deadlocked" in their interpretation of restrictive codes, then you are obligated to take the issue to the public for a decision. This may entail the enactment of new state legislation or new codes and ordinances at the local and county level.

The learning needs of the developmentally disabled are more important than the inconvenience of a battle with the bureaucracy. If you are well-informed and persistent, you will win the battle.

Some community residences have successfully ignored their non-compliance with zoning ordinances. If you choose to ignore zoning regulations, be certain that you understand the possible consequences and be prepared to deal with them.

Zoning regulations are notoriously flexible and in some cases are legally unenforceable. Your legal counsel should be able to inform you of these situations.

Many zoning regulations are enforced only at the pleasure of the community's residents and if the public has been properly prepared to support your project, you are unlikely to encounter many restrictive zoning problems.

The trade and labor unions usually exert the greatest power in securing changes in zoning regulations. Having the support of these unions is obviously a great help in resolving the dilemma of restrictive codes.

There are probably examples of community residences for mentally retarded persons which are able to function in a developmentally appropriate manner even though their "licensing label" is peculiar and seemingly inconsistent with a normalized residence. You may decide that you can live with this type of situation if the restrictions do not compromise your program. Obviously this is a decision which will have to be made on an individual basis with each facility.



## Chapter VI Summary

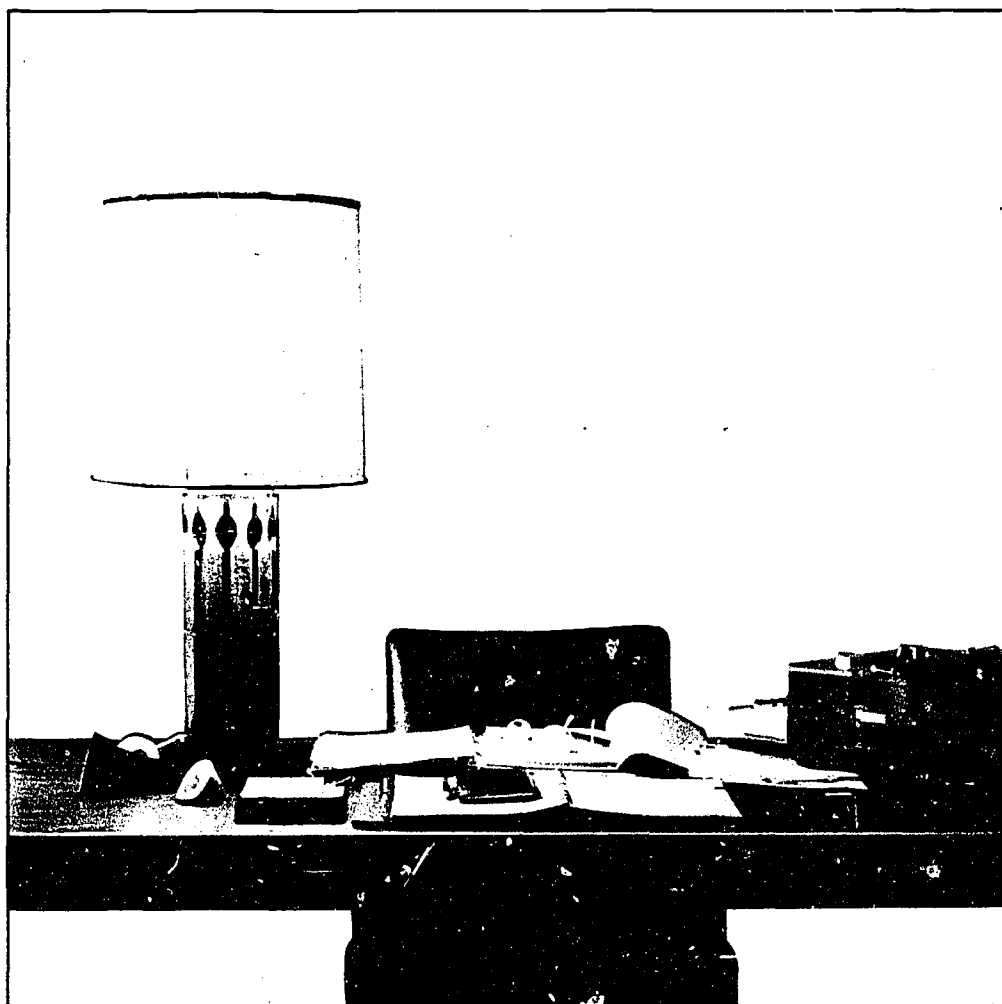
- Some searching is necessary to determine the legality of your proposal and whether it will require new legislation.
- Because of the relationship between source of funding and management control, you must explore the possible funding combinations available to your community.
- In addition to governmental sources of funding, you may wish to conduct your own fund raising campaign.
- The location of the group home is based upon the needs of individuals to learn from the environment in which they live.
- You may be able to choose which "license label" is to be applied to the group home and avoid needless hassel with restrictive codes and regulations.

### Check List:

- Determine legality of desired services.
- Identify sources of funding.
- Choose location of residential facility according to needs of resident clients.
- Study the nature and consequences of restrictive codes and ordinances.
- Choose "licensing label" before application is filed.



## VII. Administering The Service



## VII. Administering The Services

The economics, as well as the normalcy of the service delivery system, dictates that all resources of the community should be available to and utilized by the developmentally disabled. These resources should include generic services available to all citizens.

Agencies delivering specialized services must coordinate their specialities with the resources of the general community, in order that the needs of their clients may be served in a manner that is consistent with normal community experience.

*Principles of the Service Delivery System. Standards for Community Agencies Serving Persons with Mental Retardation and Other Developmental Disabilities*

The debate over who shall administer the community-based residential services has continued for several years. The answer to this debate can be found in the guiding principles which govern services.

No single approach to the administration of services can satisfy the needs of all individuals requiring those services.

Rigid adherence to one type of administration reduces the options which assure the developing independence of the mentally retarded person.

For example, Apartment Living may require agency intervention at initial stages to locate, furnish, lease or rent the facility, but at a later stage the individual should assume greater responsibility in renting and maintaining his own apartment.

The agency or agencies involved should be administratively capable of modifying their direct involvement to meet the actual needs of clients rather than forcing clients to meet the agencies' need to exert control.

The most frequent determinant of who administers services is the source or channel of monies to operate those services.

Like many other aspects of the general service delivery system, the mechanisms for funding are also changing. For example, it is predicted that state governments will exercise their responsibility by contracting for most residential services rather than providing all services through state institutions. Some states have already made major moves in this direction, notable examples being California and Illinois.

Under a contract system, the number and variety of options is dramatically increased. At the same time, one must note that under a contract system, the need for adequate monitoring of services is also increased.

Adequate and appropriate monitoring of the service system may, at first, appear to be more difficult with a diverse system which is removed from single agency authority.

In the face of such a challenge it is necessary to note that the attempts to monitor state controlled services and make them accountable, has been notoriously inadequate. It becomes obvious, therefore, that newer mechanism must be employed to monitor and evaluate services.

The evaluation of services will be discussed at greater length in Chapter IX, but you should be aware of the monitoring aspect of a service system as you consider and explore administrative mechanisms. The local and state Associations for Retarded Children

should, for example, guard their role as consumer representatives in the monitoring process. When a service is operated by the ARC, then the Association has effectively abandoned its legitimate role as monitor of that service system.

Many experts have recommended the establishment of non-profit corporations to administer the residential services system. One of the widely-known examples of this approach is the Eastern Nebraska Community Office of Retardation (ENCOR).

Where the non-profit corporation approach is utilized, it is essential that the group be strong and active to ensure the delivery of supportive services and to maintain mortgage commitments.

A modification of the above service system has been proposed by some groups. Each house or residential facility would be owned by a non-profit organization which would supervise the manager, arrange for the ongoing delivery of supportive services, and, in general, oversee and be responsible for the home and its operation.



## Mechanics of Administration

- Depending upon the community structure and the funding authority, you will need to determine whether the entire residential service system should be administered under one agency or whether each home or facility should be administered separately.

Regardless of the overall administrative structure, a clearly defined mechanism must be established to coordinate the various elements of the service system. A mechanism for relating to, and coordinating with, private proprietary facilities must also be worked out.

From its beginning, the residential service system must comply with the *Standards for Community Agencies Serving Persons With Mental Retardation and Other Developmental Disabilities*. The *Standards for Residential Facilities* are considered to be a part of the *Standards for Community Agencies*.

Decisions regarding staffing requirements cannot be appropriately determined until you have decided upon the program design of each separate facility.

The OASIS Corporation has developed a list of services for the Michigan State Housing Development Authority, and this list is presented here to aid you in visualizing the scope of services to be considered.

Home-Related Services for the Group Home Residents	Home	Community	Community Agencies and Organizations Involved
Screening and placement of residents	X	X	Community Mental Health, Department of Social Services, Parents, Dir. of State Institution
Recognition and sensitivity to resident's personal need	X		—
Counseling of residents	X	X	Community Mental Health, Department of Social Services
Special education		X	Public Schools
After hours help with course work	X		—
Social life training	X	X	Public Schools, Community Mental Health
Psychological evaluation		X	Community Mental Health
General house supervision — "authority figure"	X		—
Crises Intervention and assistance	X	X	Community Mental Health
Health care		X	County Health Department, Local hospitals, clinics and doctors
Dental care		X	Local dentists, County Health Department
Personal hygiene and appearance	X		—
Practical experience in cooking, cleaning, and laundry	X		—
Religious Services		X	Local churches
Legal Services		X	Local lawyers, legal aid services
Financial counseling and money management	X		—
Working with agencies providing direct payments to resident	X		—
Reporting of resident's income to Social Services	X		—
Keeping resident records and progress reports	X		—
Arranging for change in placement	X	X	Community Mental Health, Department of Social Services, Parents, Residential Program Association
Parent orientation and ongoing liaison with parents	X	X	A.R.C., Residential Program Association
Transportation	X	X	Public transportation
Leisure-Related Services			
Planning recreation and entertainment	X		—
Providing recreation and entertainment	X	X	Community Service Organizations, Volunteers
Providing chaperoning for field trips and special events	X	X	Community Service Organizations, Volunteers
Liaison with community organizations providing leisure time activities	X		—
Counseling on dating	X	X	Community Mental Health
Hobby skills development	X	X	Community Mental Health, volunteer groups, Community Service Organizations
Transportation	X	X	Public transportation
Work-Related Services			Community Agencies and Organizations Involved
Work Training		X	Voc. Rehab., Community Mental Health, Public School System, Sheltered Workshop
Job information and placement	X	X	Voc. Rehab., Community Mental Health, Mich. Employment Security Commission, Sheltered Workshop
Sheltered and non-sheltered employment		X	Voc. Rehab., Community Mental Health, Sheltered Workshops, private companies
Recordkeeping on resident's progress	X	X	Voc. Rehab., Community Mental Health, Sheltered Workshops
Liaison with employers, workshops and Training centers	X	X	Voc. Rehab., Community Mental Health, A.R.C.
Transportation	X	X	Public Transportation, Private transportation firms
Home-Related Services for Group Home Program			
Program design	X	X	Community Mental Health, Inter-Agency Committee, A.R.C., Dept. of Social Services, MSHDA, Residential Program Association
Budget preparation and financial planning	X	X	Community Mental Health, Department Social Services, MSHDA, Residential Program Association
Budget approval		X	Department Social Services, Community Mental Health, Residential Program Association
Accounting and recordkeeping of program	X		—
Monitoring quality of output	X	X	Community Mental Health, Department of Social Services, A.R.C., MSHDA, Residential Program Association
Consulting to sponsor		X	Community Mental Health, Department of Social Services, Inter-Agency Committee, MSHDA, Residential Program Association
Securing permits and licenses and meeting standards	X	X	Residential Program Association
Purchasing supplies and services	X		—
Meal planning, preparation, and service	X		—
Laundry service	X		—
Housekeeping and internal maintenance	X		—
External maintenance and groundskeeping	X	X	Private firms
Supervising of staff	X		—
Coordinating volunteers	X		—
Public relations with community	X	X	Community Mental Health, A.R.C., Residential Program Association
Liaison with parent groups	X		—
Communication with other group homes	X	X	A.R.C., Department of Social Services, Department Mental Health, MSHDA, Residential Program Association
Assuring that outside services are provided as needed	X	X	Residential Program Association
Responding to emergencies at the home	X		—

Prepared by the OASIS Corporation for the State of Michigan

An analysis of the services to be considered indicate that:

1. In-home services\* include more than room and board and should be funded accordingly;
2. Since many services may be provided both in the home and in the community, good coordination and communication are necessary between the home and community agencies;
3. Since a number of critical in-home services may be provided, a competent and cohesive staff is required.

- The staff required to provide the in-home services should be defined as part of the program plan.

In order to develop a staffing pattern, an analysis of the in-home services should be made to determine which staff should handle the planning, implementation, and evaluation functions for each of these services.

The following lists represent examples of staff functions which you can use to develop your own plans. You may wish to delete or expand certain areas in keeping with the requirements of your community's residential service needs. You should develop functional job descriptions for all staff positions.

Functions of a Residential Director (for a multi-home system):

- Coordinates office staff and routines.
- Coordinates professional activities.
- Supervises, coordinates and directs house managers in each home.
- Meets with staff members of each house periodically.
- Works closely with a Citizen Advisory Board.

Functions of a House Manager:

- Is responsible for a smooth-running house to meet the needs of each household member.
- Is responsible for arranging or securing transportation to and from work (or program) for each resident.
- Meets with social workers and residential director concerning needs of residents.
- Knows when to call for help or answers before problems get out of hand.
- Is responsible for helping residents in their money management and banking.
- Is responsible for shopping and meal planning, and ensures that residents are involved in learning to shop and plan meals.
- Is responsible for upkeep of the house and direction of other employees.
- Coordinates and supervises volunteer activity.

Functions of a Social Worker:

- Provides counseling to all residents.
- Maintains a control registry of information and vital data on residents. Keeps regular progress reports on each resident.
- Makes frequent contacts with employers of residents.
- Does information and agency referral and case follow-up (i.e., when and if a resident does not benefit from a particular environment at one of the residences, the case is not completely dropped, rather it is carried on by seeking another type of placement for the person).
- Assists in crisis situations.

\*In-home services are those services and activities which are provided within the group home or under the direct supervision of the group home staff. School, workshop and similar out-of-the-home activities would not be a part of in-home services.

- Assists in the screening of possible candidates for house placement.
- Meets with parents, guardians, social workers, etc., of possible candidates to talk over the programs.
- Maintains close contact with social agencies, employers, workshops, training centers and parents.
- Sets up appointments, medical examinations, psychological testing, dental services, etc.

The staff may include other houseparents, housekeeper, cook, etc. The roles of these staff should be obvious enough that their job descriptions will flow naturally from the documented need of your proposal.

In the case of a small group home which does not require a large staff, there will undoubtedly be a grouping of functions.

The staffing for a group home should be adequate to handle all of the in-home services without relying on volunteer help. However, the broad and appropriate involvement of volunteers is an important aspect of your program plan.

- Volunteers provide an ongoing contact and informal communication network with the larger community.
- Volunteers actively exert their influence in telling others about the work they are doing to help mentally retarded persons. This type of social interaction represents a powerful and constructive public education technique. A well-informed and socially responsive community will guarantee the autonomy and stability so necessary to the long-term success of the residential service system.
- Volunteers may be active in the in-home teaching program, working directly with specific individuals to develop self-help and social skills.
- Volunteers provide an opportunity to residents to visit in other homes and to gain greater understandings of appropriate social behavior.
- Volunteers have been actively involved in various recreational programs as well as arranging for social contact between retarded and non-retarded peers.

## Chapter VII

### Summary

- Rigid adherence to one type of administration reduces the options which assure the developing independence of retarded individuals.
- Regardless of the overall administrative structure, a clearly defined method must be established to coordinate other service needs for residents of the group home.
- In order to develop a staffing pattern, an analysis of in-home activities should be made.
- The involvement of volunteers is an important aspect of your program plan.

#### Check List:

- Determine how residential service system should be administered.
- Develop a program design for each facility.
- Develop functional job descriptions for all staff positions.



## VIII. Operating the Program





## VIII. Operating The Program

### Selecting Residents

There are many theories about who should be chosen as the initial residents of a community's first group home. Some say the resident clients should be selected on the basis of potential to succeed in the community setting. Others say that the first resident clients should be young children so as to gain more public acceptance of the program.

Although these strategies may need to be considered, neither of them is based on a primary concern for the individual. The priority needs of the community's citizens should be the basis for selection.

The survey discussed in Chapter II should reveal to you the first resident clients of the initial facility and of all those following.

It is probably necessary to establish certain criteria by which individuals will be selected for admission to the facility. There are many relevant variables for use in determining who will participate in a particular group home experience.

Remember that the establishment of criteria for admission is simply another way of establishing criteria for *exclusion* from services.

The grouping of residents within one home setting requires both planning and ingenuity. Your guiding premise is to provide a service which meets the learning needs of the community's mentally retarded citizens; therefore, you should exercise great care in establishing the criteria you may use to exclude individuals from a particular service.

Some authorities maintain that mixing a group on the basis of age is more in keeping with the average home where there are individuals ranging in age from infancy to adulthood. However, one must bear in mind that the dynamics of an average home are not necessarily operative in a group home for mentally retarded persons.

It is virtually impossible to reconstruct the dynamics of an average American home if you are dependent upon the regular changing of personnel and a constant milieu of widely varying communication abilities. Perhaps the small foster home is the nearest duplication of the "average" family.

Recognizing the possible limits placed upon structuring the dynamics of an average home should allow you to plan an environment which will teach those concepts and behaviors that are usually dependent upon the emotional ties and role modeling found in the average family.



Approximately two years ago Jeff was just another six-year-old retarded boy with hydrocephalus staring aimlessly at the ceilings and walls of one of the overcrowded, understaffed wards of a state institution.

Today Jeff is out of the institution and is living in a comfortable home environment with five other mentally retarded children and their houseparents. Jeff has conquered many barriers and has learned to dress himself and walk on his own. His speech has improved greatly along with hand-use and coordination. He relates well with others both in school and home environments and has learned many social skills which allow him a much wider social experience. Jeff is now attending special classes in the public schools.



There are also limitations imposed by not having highly skilled teachers functioning as houseparents and supportive staff. You may discover that greater attention to learning needs can be achieved if at first the staff is not forced to deal with a wide range of developmental levels and communication abilities for which they are unprepared.

Your awareness of these factors does not imply that a highly homogenous group is either necessary or developmentally appropriate. For example, the inclusion of two or three non-ambulatory young adults in wheelchairs, within a larger group of ambulatory young adults is quite appropriate since it provides the opportunity for many learning experiences for all of the residents.

Consideration should be given to the factors which allow for the development of group identity as well as for individual identity. Activities within the home must provide a secure relationship between individual residents and between residents and staff. The ever-present threat of identity loss in a residential facility must be constantly assessed and corrected as necessary.

As a regular emphasis is placed upon inservice education for staff development, the houseparents and other teachers should be able to respond to learning needs in a more developmentally efficient manner. As staff competency increases, the diversity of learning needs among resident clients can also be increased.

You may wish to examine the following categories of current skills development to assist you in planning program options as well as establishing admission criteria.

## Categories of Current Skills Development

### A. Communication Skills

- Able to express self well and communicate with others.
- Able to communicate at a gross level but demonstrates understanding of others.
- Has not developed any effective communication skills.

### B. Self-Help Skills

(includes: personal hygiene, dressing skills, eating skills, toileting skills, etc.)

- Self-reliant.
- Needs minimal assistance or assistance in only selected areas.
- Needs total assistance.

### C. Social Skills

- Demonstrates an understanding of the basic dynamics of social interaction and is adequately skilled to participate independently in a social setting.
- Able to interact acceptably in a one-to-one interpersonal situation, but lacks understanding of other social skills.
- Shows little evidence of understanding the appropriate behaviors necessary for social independence.



It should become obvious that a broad range of physically handicapping conditions can be included within a small group which may all share the need to develop certain skills or can evolve a peer group identity in spite of marked individual differences.

## Program Considerations

Although it is not the purpose of this handbook to study program design, it is important to understand the critical nature of the program needs of resident clients.

The community living situation should provide an environment within the community where the individual resident can achieve a sense of identity and security. In this environment the mentally retarded person can satisfy more of his personal needs and aspirations.

A residential facility can maximize independence, community involvement and responsibility for one's own actions.

An environment where learning and genuine caring for the individual takes place, occurs only when that environment is planned. Creating a living situation which is conducive to the continuing development of the individual demands staff with commitment and skill in creating this environment.

A first step in assuring the necessary generic services for a successful community-based residential service may entail a concerted educational effort with the professional community.

The early involvement of the professionals, including those identified in Chapter IV, will provide the mechanism for getting the word to the community's professional leadership.

It may be very beneficial to host a series of workshops in which each discipline conducts its own educational encounters in the search for developing the necessary services.

Each professional service, plus each relevant agency, should become responsible for proposing the approaches to meet the needs of the resident clients of your residential service system.

A careful study of the *Standards for Community Agencies Serving Persons With Mental Retardation and Other Developmental Disabilities* will reveal the content and direction for your professional education activities.

An increasing integration of the residential facility into the larger community is necessary to assure an appropriate service system.

Integration of the handicapped person into the mainstream of society demands the utilization of generic community resources and services.

Every effort should be made to use community medical, dental, educational, recreational and employment resources to meet the needs of the mentally retarded citizen.

The mentally retarded person should be educated in the regular community schools, should receive needed medical and dental care in community clinics and hospitals, and should use community recreation and entertainment resources in his leisure time.

- One of the primary goals of all specialized services for the handicapped person is to develop appropriate generic resources in the community so that non-integrative special programs and services may be discontinued.

Plan to consult with a variety of authorities in planning the program and keep the learning needs of the individual constantly in mind.



## Chapter VIII Summary

- Residents of the group home are initially selected according to greatest community need and current program opportunities.
- Staff members also need developmental programs and their continuing education is a critical part of your concerns.
- An environment where learning and genuine caring for the individual takes place, occurs only when that environment is planned.
- The community's professional leadership may need to conduct its own educational program to develop necessary services.
- Integration of the mentally retarded individual into the mainstream of society demands the use of generic resources and services.

### Check List:

- Determine the basis for selection of initial resident clients.
- Study critical program needs of resident clients.
- Consult with variety of authorities in planning programs.
- Contract for needed services.

## IX. Evaluating The Program





## IX. Evaluating The Program

The evaluation process can be distilled to discover its essence — the individual.

While there may be a variety of monitoring and assessment activities surrounding the residential program, the only true evaluation comes with answering the right questions.

What criteria do you apply to evaluate these services?

It's very simple. Apply the same standards you would for any other citizen.

"If you wouldn't design it for your own home and family, don't design it for the retarded person."

1. Would you live there?
2. How has participating in this program helped the individual resident increase the various skills required for daily living?
3. What can the individual do now that he could not do before?
4. Do the residents do all they can for themselves?
5. Are they growing and learning?

These questions lead to an evaluation of "program results" as opposed to an evaluation of "program activities."

The attempt to evaluate residential services on the basis of "activities performed," is rather like evaluating a plumber's services on the basis of "how many tools he used." It is obviously a dangerous and misleading approach to evaluation.

There is, of course, a reasonable place in the total evaluation for an assessment of the environment and the types of activities occurring within it. This type of assessment is, however, more akin to "preventive maintenance" than it is to evaluation. One of the responsibilities of the sponsoring agency and the community monitors is to maintain an active awareness of the day-to-day and week-to-week activities as well as an awareness of the environment in which these activities occur. It is essential, of course, to eliminate or avoid any architectural barriers in the facility.

It is obvious that the environment should be as safe as is reasonable for a regular community residence. Just as obvious is the need for a healthy environment—both physically and psychologically.

Perhaps a few words are necessary here regarding the effect of codes and legal restrictions upon the evaluation process. By separating the critical areas of individual assessment from an assessment of the physical space, you are more able to determine whether certain legal restrictions are helping the program, interfering with program success, or irrelevant to the program.

Safety codes, licensing standards and accreditation standards are different types of efforts which the public uses to assure itself that services are appropriate and responsive to the needs of the developmentally disabled citizen.

Where any code or standard seems inappropriate or restrictive to developmental programs, then that code or standard can and should be changed. That's why things are evaluated in the first place—to find areas which need changing to improve the program.

Your group should be cautioned, however, to avoid fighting to change codes or standards without a full understanding of the consequences of those changes.



An effort to alter certain restrictions simply because they are inconvenient or because they are not compatible with some preconceived solution or program, is not always a justifiable means of solving the problem.

*Understand the thing you wish to change and the consequences of that change before you embark on a great flurry of activity which may be wasted in the long-run.*

An active and "living" service program evolves according to the expressed needs of its clients, along with the evolving community and the larger society. Your evaluation should take these factors into consideration as you interpret the information you collect.

There is no rational place in society for the static, routine-oriented service delivery system which forces conformity on those it touches.

Change is natural and desirable, not for change itself, but because the people the program serves become more autonomous as they change in a constructive direction.

The accreditation standards for community services endorse the concept of an evolving service delivery system and see program results as the primary evidence of the system's responsible operation.

### Monitoring the Service

Monitoring a residential service for mentally retarded persons is an enormous responsibility because that service is shaping and influencing the personal competencies and future lives of our children and fellow citizens.

The monitoring process would perhaps be less crucial if we were assessing radishes or rats, but we are assessing the quality of life and the future abilities of people—people who are vulnerable to our awareness of their problems or to our lack of awareness.

Here are some thoughts on monitoring:

- The public, represented by state government, has an obligation to regularly monitor all aspects of the human services delivery system.
- The local ARC, supported by its state and national organizations, has a primary responsibility to conduct a continuous assessment of services for the mentally retarded individual. As a legitimate voice of consumer representatives, the ARC must maintain an objective and critical monitoring process to assure the appropriateness of the residential service system and its individual programs.
- The sponsoring agency and the individual facilities must also design an ongoing assessment procedure. The facility should be constantly aware of the effects of its operation on the lives of its clients.

The local ARC, through its Residential Services Committee, can provide appropriate monitoring for each residential facility. The monitoring process can, and should be, a pleasant and cooperative venture with staff of the facility. However, when it comes to basic issues, the friendship with agency personnel cannot be permitted to overshadow or protect faults within the service.

- Through workshops and seminars, prepare ARC members to understand and apply the relevant *Standards for Residential Facilities* (AC/FMR).

A careful study of the Standards will prepare you to conduct a valid and useful assessment of the residential service.

- Involvement in the NARC project, *Parent Training in Residential Programming*, and a careful study of the four booklets from this project will serve as a guide in the monitoring process.
- As new technology, new opportunities and new learning needs emerge, the ARC should be able to support and encourage program changes which are appropriate.
- An application of the basic principles discussed in Chapter I will provide you with the basic guidelines against which you evaluate services to mentally retarded persons.
- Develop a review system to assure that those persons who exercise the responsibility to monitor services have an opportunity to discuss their observations and findings with other members of the association. A review process of this type will help the monitor to remain alert to his task and will provide a wider range of understanding to interpret the evidence collected by the monitor.
- From the beginning the monitoring effort should ensure that the residential services are involved in the AC/FMR accreditation process. Accreditation is currently the best way to identify an appropriate service program.

A few examples have been extracted from the *Standards for Residential Facilities* to assist you in visualizing your task as monitors of residential services.

- 2.1.1 The primary responsibility of the living unit staff shall be to devote their attention to the care and development of the residents.

*There are five Standards under this heading which focus upon the appropriate role of the in-home staff members.*

- 2.1.2 Members of the living unit staff from all shifts shall participate with an interdisciplinary team in appropriate referral, planning, initiation, coordination, implementation, follow-through, monitoring, and evaluation activities relative to the care and development of the resident.

*Many of the Standards relate to the necessity for cooperation and planning in the development of programs.*

- 2.1.3 The "rhythm of life" in the living unit shall resemble the cultural norm for the residents' nonretarded age peers, unless a departure from this rhythm is justified on the basis of maximizing the residents' human qualities.

- 2.1.3.1 Residents shall be assigned responsibilities in the living units commensurate with their interests, abilities, and developmental plans, in order to enhance feelings of self-respect and to develop skills of independent living.

- 2.1.3.2 Multiply handicapped and nonambulatory residents shall:

- 2.1.3.2.1 Spend a major portion of their waking day out of bed;

- 2.1.3.2.2 Spend a portion of their waking day out of their bedroom areas;

- 2.1.3.2.3 Have planned daily activity and exercise periods;

- 2.1.3.2.4 Be rendered mobile by various methods and devices.

- 2.1.3.3 All residents shall have planned periods out of doors on a year-round basis.

- 2.1.3.4 Residents should be instructed in how to use, and, except as contraindicated for individual residents by their program plan, should be given opportunity for, freedom of movement;
- 2.1.3.4.1 Within the facility's grounds;
  - 2.1.3.4.2 Without the facility's grounds.
- 2.1.3.5 Birthdays and special events should be individually observed.
- 2.1.3.6 Provisions shall be made for heterosexual interaction appropriate to the residents' developmental levels.
- 2.1.4 Residents' views and opinions on matters concerning them should be elicited and given consideration in defining the processes and structures that affect them.
- In order to assure that individuals learn how to make decisions, they must be provided an ongoing opportunity to practice decision-making skills.*
- 2.1.5 Residents should be instructed in the free and unsupervised use of communication processes. Except as denied individual residents by team action, for cause, this should typically include:
- 2.1.5.1 Having access to telephones for incoming and local outgoing calls;
  - 2.1.5.2 Having access to pay telephones, or the equivalent, for outgoing long distant calls;
  - 2.1.5.3 Opening their own mail and packages, and generally doing so without direct surveillance;
  - 2.1.5.4 Not having their outgoing mail read by staff, unless requested by the resident.
- An individual's ability to communicate his needs, interests and concerns is a critical area for teaching. He needs to take advantage of many opportunities to practice and to improve these skills.*
- 2.1.8.8 Chemical restraint shall not be used excessively, as punishment, for the convenience of staff, as a substitute for program, or in quantities that interfere with a resident's habilitation program.
- 2.1.8.9 Behavior modification programs involving the use of time-out devices or the use of noxious or aversive stimuli shall be:
- 2.1.8.9.1 Reviewed and approved by the facility's research review and human rights committees;
  - 2.1.8.9.2 Conducted only with the consent of the affected resident's parents or surrogates;
  - 2.1.8.9.3 Described in written plans that are kept on file in the facility.
  - 2.1.8.9.4 Restraints employed as time-out devices shall be applied for only very brief periods, only during conditioning sessions, and only in the presence of the trainer.
  - 2.1.8.9.5 Removal from a situation for time-out purposes shall not be for more than one hour, and this procedure shall be used only during the conditioning program, and only under the supervision of the trainer.
- Any area of programming which may involve restrictions of individual rights should be carefully evaluated in terms of benefit to the individual rather than benefit to the staff.*
- 2.2.4 Residents shall be provided with systematic training to develop appropriate eating skills, utilizing adaptive equipment where it serves the developmental process.

*Every aspect of the daily activities can and should be utilized as a learning experience which moves the individual steadily forward in his development.*

**2.3.2 Residents shall be trained and encouraged to:**

2.3.2.1 Select and purchase their own clothing as independently as possible, preferably utilizing community stores;

2.3.2.2 Select their daily clothing;

2.3.2.3 Dress themselves;

2.3.2.4 Change their clothes to suit the activities in which they engage;

2.3.2.5 Maintain (launder, clean, mend) their clothing as independently as possible.

2.4.1 Residents shall be trained to exercise maximum independence in health, hygiene, and grooming practices, including bathing, brushing teeth, shampooing, combing and brushing hair, shaving, and caring for toenails and fingernails.

2.4.7 Provisions shall be made to furnish and maintain in good repair, and to encourage the use of, dentures, eyeglasses, hearing aids, braces, etc., prescribed by appropriate specialists.

These are only a few of the Standards for Residential Facilities. You will find a wealth of information for your evaluation process by studying the entire document.

## Chapter IX Summary

- While there may be a variety of monitoring and assessment activities, the only true evaluation comes with answering the right questions.
- The evaluation process should be viewed as a very constructive activity—it identifies the value of programs and determines areas needing improvement.
- Change is natural and desirable, not for change itself, but because the people served by the program become more independent as they learn.
- Monitoring a service is an enormous responsibility because that service is shaping the lives of our children and fellow citizens.
- An application of the basic principles (Chapter I) will provide the guidelines for evaluating services.

### Check List:

- Establish the criteria for evaluating the service.
- Evaluate the effects of restrictive codes and regulations upon the program.
- Plan to become involved in the accreditation process.
- Develop strategies and locate the responsibility for regular monitoring of the services.

## Conclusion

The task of changing *anything* is not easy. When faced with new ideas, preconceptions, or prejudices, it is easiest to give in to them and to reinforce them; it is more difficult to acknowledge those prejudices and to try to accommodate to them; it is extremely difficult and sometimes impossible to alter them and bring about actual social change.

No one ever said that important things are easy. Attempting to provide a richer, fuller life for retarded citizens of the United States requires an immense amount of work. It must be carefully done, and must not violate the rights and privileges of either the retarded citizen or his other fellow citizens in the community.

There are no simple rules for successful social change on behalf of mentally retarded persons. The rules which work in California may not work in Vermont, and what works in Nebraska may not work in Oregon. No guidelines can tell you how to succeed in your community. The responsibility for knowing the facts, for studying your own community, and for finding the best possible solution for where and how the mentally retarded citizen should live in your area, rests squarely upon the shoulders of you and your friends.

Only you know why working on this project is important to you. There will be times when you will suffer disappointments, and will meet frustrations and resistance. At times the work will be solitary, and late in the night as you labor on reports, telephone lists, or baking cookies and cakes to raise money for a public information campaign, you will wonder, "What am I doing here? What is the deal? Why is it necessary that such large amounts of time and human energy have to be expended to secure what should be a God-given democratic right for my retarded child?"

After you have asked all these questions for the thousandth time, you will steadily continue with your work because the task is clear, the need is great, and you are the kind of person who goes after what is right.

Good luck.

# Glossary

Insofar as possible, technical or specialized terms employed in these Guidelines are used in accordance with the definitions given in Webster's Seventh New Collegiate Dictionary (Springfield, Mass.: G. & C. Merriam, 1964), or are defined in the context in which they occur. Terms defined in this Glossary include: (1) terms whose dictionary definition is inadequate or ambiguous for the purposes of the Guidelines; and (2) terms that require fuller definition, exemplification, or reference than it is feasible to provide in the text. Glossary definitions are intended to give the meaning of such terms as they are used in these Guidelines and in the Accreditation Standards.

**Advocacy**—That which is done by an advocate: an individual, whether a professional employed by a private or public agency, or a volunteer who acts on behalf of a resident to secure both the services that the resident requires and the exercise of his full human and legal rights.

**Agency**—An organization that provides services to persons with mental retardation and other developmental disabilities, or to their families. The agency need not limit its services to the developmentally disabled; it may serve the developmentally disabled as part of the general public to which it offers services.

**Ambulatory**—Able to walk independently, without assistance.

**Client**—A person who is mentally retarded or otherwise developmentally disabled, and who needs some form of specialized or generic service related to his mental or physical impairment.

**Community**—A general population having a common interest or interdependency in the delivery of services.

**Cross-Disciplinary Approach**—A method of delivering services in which one or two members of an interdisciplinary team serve as team facilitators to implement the program plan between regularly scheduled re-evaluation sessions by the team. Other members of the team teach and share their specialized professional skills with, and release their intervention role to, the facilitator(s) during this period, while maintaining their professional (or credentialed) accountability on behalf of the client and his family.

**Culturally Normative**—That which is normal, typical or usual for a given culture, such as the attitudes, performances, or behaviors ordinarily displayed by or expected of most individuals within a given culture.

**Developmental Disabilities**—Disabilities that become evident in childhood, are expected to continue indefinitely, constitute a substantial handicap to the affected individual, and are attributable to mental retardation, cerebral palsy, epilepsy, or other neurological condition closely related to, or requiring treatment similar to that required by, mental retardation.

**Disabled Person**—A person with one or more developmental disabilities.

**Discipline**—A field of study or a subject that is taught.

**Environment**—The aggregate of social and cultural conditions that influence the life of an individual or group.

**Functional Level**—The effectiveness or degree to which the individual is able to perform necessary personal or social skills.

**Generic Services**—Services offered or available to the general public, as distinguished from specialized services that are intended only for the disabled.

**Habilitation**—A teaching and learning process designed to equip an individual with useful and constructive skills.

**Interdisciplinary Approach**—An approach to diagnosis, evaluation, and individual program planning in which professional

and other personnel participate as a team. Each participant, utilizing whatever skills, competencies, insights, and perspectives his particular training and experience provide, focuses on identifying the developmental needs of the person and devising ways to meet them, without constraints imposed by assigning particular domains of behavior or development to particular disciplines only. Participants share all information and recommendations, so that a unified and integrated habilitation program plan is devised by the team. The interdisciplinary approach is contrasted with the multidisciplinary approach, in which each representative of a particular discipline or program views the person only from the perspective assigned to his discipline or program; in which particular domains of individual development and behavior are often held to be the sole responsibility or prerequisite of particular professions or programs; and in which each representative of a discipline separately reports his findings and the recommendations that he proposes to implement as a result, more or less independently of the findings and recommendations reported by other representatives. A single staff member may then use this accumulated knowledge to formulate a program plan.

**Monitor**—To watch, observe or check the activities and consequences of a program or a service.

**Nonambulatory**—Unable to walk independently, without assistance.

**Normalization**—The concept of helping the developmentally disabled persons to obtain an existence as close to the normal as possible, making available to them patterns and conditions of everyday life that are as close as possible to the norms and patterns of the mainstream of society. Specifically, the use of means that are as culturally normative as possible to elicit and maintain behavior that is as culturally normative as possible.

**Program**—A structured set of activities to achieve specific objectives, relative to the developmental needs of the clients served by an agency or service.

**Residential Facility**—A facility that provides twenty-four hour programming services, including residential or domiciliary services directed to enhancing the health, welfare, and development of persons with mental retardation or other developmental disabilities. While the facility must provide twenty-four hour programming for residents, in accordance with their needs, it need not itself operate any programs or services other than residential or domiciliary.

**Rhythm of Life**—Relating to normalization. Providing a normal rhythm of the day (in respect to arising, getting dressed, participating in play and work activities, eating meals, retiring, etc.), normal rhythm of the week (differentiation of daily activities and schedules), and normal rhythm of the year (observing holidays, days with personal significance, vacations, etc.).

**Service Delivery System**—The total array of service components, specialized and generic, that is directed toward meeting the general and extraordinary needs of the disabled.



# References

- Assessing the Potential of the Consumer in Developing Priorities for Services for the Retarded.* Prepared by Arthur Bolton Associates in cooperation with The California Association for the Retarded. The Alta California Regional Center. March, 1971.
- An Auspicious Live-In: A Developmental Model for Community Residential Living.* Charles J. Seevers, Ph.D., Elkhart County Association for the Retarded, Inc., P.O. Box 398 Bristol, Indiana 46507. Madison-1973.
- Buckout, Robert. *Toward Social Change.* New York: Harper & Row, Publishers, 1971.
- Cohen, J.S., Butler, I., Deline, S. & Nutter, R.E. *Benefit—Cost Analysis for Mental Retardation Programs.* Ann Arbor Michigan: Institute for the Study of Mental Retardation and Related Disabilities. The University of Michigan, 1971.
- Community Residential Services.* Developmental Disabilities Training Institute, University of North Carolina in cooperation with Pennsylvania Division of Mental Retardation. May, 1973.
- The Complete Fund Raising Guide.* Howard R. Mirkin. Public Service Materials Center, 104 East 40th Street, New York New York 10016.
- A Comprehensive Residential Services Plan for St. Joseph County.* Council for the Retarded of St. Joseph County, 1235 North Eddy Street, South Bend, Indiana 46617. September, 1972.
- Des Jardines, Charlotte. *How to Organize An Effective Parent Group & Move Bureaucracies.* Co-ordinating Council for Handicapped Children, 407 South Dearborn. Room 950, Chicago, Illinois 60615. (\$1.50)
- Elkin, Robert & Cormick, Delroy. *Analyzing Costs in a Residential Group Care Facility for Children.* Child Welfare League of America, Inc. 67 Irving Place, New York, New York. 1969.
- Fine Points of Publicity.* National Association for Retarded Children, P.O. Box 6109, Arlington, Texas 76011. 1970. (25 cents)
- Guidelines to Community Living Systems for the Developmentally Disabled.* Madison, Wisconsin: Wisconsin Department of Health and Social Services, Bureau of Mental Retardation, January, 1973.
- The Initiation and Development of a Comprehensive, County-wide System of Services for the Mentally Retarded of Douglas County (Nebraska).* Greater Omaha Association for Retarded Children, Inc. Vol I & II. 1970.
- McAvoy, James. *Alternatives to Institutionalization: Community Residences.* (Speech). Peninsula Association for Retarded Children. Hampton, Virginia. May 8, 1973.
- Mental Retardation Survey, 1971.* Tarrant County, Texas, Mental Health—Mental Retardation Center.
- The MSHDA-N.P. Residential Program for the AMR Report. OASIS Corporation, Ann Arbor, Michigan. June 30 1972.
- Our Human Resources: Indiana Mental Retardation Residential Services Planning Project,* Final report. Indianapolis, Indiana: Division of Mental Retardation, Indiana Department of Mental Health. June, 1972.
- A Program Statement for the Establishment of Community Based Residential Services for the Mentally Retarded of Montgomery County, Maryland.* Silver Spring, Maryland: Montgomery County Association for Retarded Children. September, 1971.
- Residential Programming for Mentally Retarded Persons.* (4 booklets). National Association for Retarded Children, P.O. Box 6109, Arlington, Texas 76011. 1972. (\$1.50 per set).
- Residential Services—Group Home Seminar.* NARC Northeast Region. New York City. New York: Saturday, January 27, 1973.
- Rhode Island Community Residences Coordinator Grant: Interim Report.* Cranston, Rhode Island: Cranston Chapter for Retarded Children, Inc., February, 1973.
- Roos, P., Patterson, E.G., and McCann, B.M. *Expanding the Developmental Model.* National Association for Retarded Children, P.O. Box 6109, Arlington, Texas 76011.
- Scheerenberger, R.C. *A Study of Generic Services for the Mentally Retarded and Their Families.* Division of Mental Retardation Services, Department of Mental Health, Springfield, Illinois. May, 1969.
- Sokoloff, David A. *The Process Toward a Design of Residential Facilities for the Developmentally Disabled.* Minnesota Association for Retarded Children, Inc. December, 1972.
- Sorensen, James E., & Phipps, David W. *Cost-Finding and Rate-Setting for Community Mental Health Centers.* Association of Mental Health Administrators, 2901 Lafayette Avenue. Lansing, Mich. Jan. December, 1971.
- Standards for Community Agencies Serving Persons With Mental Retardation and Other Developmental Disabilities.* The Accreditation Council for Facilities for the Mentally Retarded, 875 North Michigan Avenue, Chicago, Illinois 60611. July, 1973. (\$3.50)
- Standards for Residential Facilities for the Mentally Retarded.* The Accreditation Council for Facilities for the Mentally Retarded, 875 North Michigan Avenue, Chicago, Illinois 60611. May, 1971. (\$3.50)
- A Study of Georgia's Services for the Mentally Retarded.* The Atlanta Association for Retarded Children, Inc., Suite 369, First National Bank Building, 315 West Ponce de Leon Avenue, Decatur, Georgia 30030. January, 1972.

## Appendix A

### COMMUNITY SERVICES CHECKLIST

While all of these services may not be necessary to the operation of a residential program, they do influence the nature of specific community needs. For example, if the community has a variety of day programs for infants and children, the need for residential services may be less for this age group. Also, the availability of counseling and parent-education services is likely to significantly affect the types of residential programs needed.

You are also urged to explore the long-term effects of one service upon another. For example, the presence of a good diagnostic service for infants will create a need for infant programs and parent counseling.

Remember too that vocational training and sheltered employment may be essential to the operation of group homes for adults just as school programs are essential to the child and adolescent development homes.

#### I. Services for infants and pre-school children

- Diagnostic and evaluation services
- Special nursery and pre-school classes
- Home training
- Home nursing
- Parent counseling
- Parent discussion groups
- Trained babysitter pool
- Medical and dental management
- Child welfare services
- Foster home care and respite care

#### II. Services for school age children

- Special school programs
- Developmental day programs for severely and profoundly retarded and/or multihandicapped children
- Homemaker services
- Special therapies such as speech, occupational or physical therapy
- Recreation programs
- Scouting
- Foster home care
- Residential services, including respite care

#### III. Services for adolescents

- Special school programs
- Counseling services

- Prevocational evaluation and training

- Sheltered workshops
- Activity centers
- Advocacy program
- Sex education programs
- Youth groups, recreation and social clubs
- Pre-marital and genetic counseling
- Guardianship and protective services
- Residential services including respite care

#### IV. Services for adults

- Special adult education programs
- Vocational evaluation, training and placement
- Social habilitation programs
- Sheltered employment
- Recreation and social activities
- Legal counsel
- Supportive services: meals, homemaking, medical, dental, etc.
- Advocacy program
- Guardianship and protective services
- Residential services

For a more detailed list of other services, examine the *Standards for Community Agencies...* (Accreditation Council for Facilities for the Mentally Retarded).

## Appendix B

## SAMPLE PLANNING BUDGET FOR COMMUNITY RESIDENTIAL FACILITY FOR SIX PERSONS

HOUSING	CAPITAL INVESTMENT	MONTHLY COST	ANNUAL COST
Housing (approx. 4 bedrooms, 8 rooms and basement) including land	\$42,000*	\$401 (15 yr. loan at 8%)	\$4,817
Furnishings and equipment (est. \$1,000 per room)	8,000	(cash or bank loan)	
Heat		20	240
Electricity		20	240
Water		15	180
Telephone		12	144
Repairs and Maintenance (2½%)		88	1,050
Repairs and replacement of furniture (10 yrs. life or 1/10 of \$8,000).		67	800
Household Supplies		35	420
Insurance (house contents, liability, group life)		63	750
<b>MANAGEMENT</b>			
Live in house/parents (couple) receives room, board, 1 wk. vacation		400	4,800
Relief parents for equiv. 2 days per wk. 24 hrs. — \$16. per day, 111 days.		148	1,776
Third level management, if needed		240	2,880

\*If any part of the \$42,000 is paid in cash, yearly and monthly costs would be reduced. At the end of 15 years, the building will be owned.

PERSONAL LIVING	CAPITAL INVESTMENT	MONTHLY COST	ANNUAL COST
Food, \$1.50 per person daily (8 people)		\$ 364	\$ 4,368
Clothing for 6 (\$15 per mo. each)		90	1,080
Medical (group plan) \$150 x 8 = \$1,200		100	1,200
Physical (outpatient) \$50 x 6		25	300
Dental \$40 x 6		20	240
Optical \$40 x 6		20	240
Sundries (hair cuts, cigarettes, etc.) \$8 per month		48	576
Recreation, entertainment (\$1 per day per person)		183	2,190
<b>TRANSPORTATION</b>			
To and from work, recreation, etc. (9 passenger van)		\$ 3,800 or payment to another source	
Repairs, ins., gas, oil		70	840
Replacement fund 12,000 miles (7¢ per mile)		70	840
<b>MISCELLANEOUS AND EMERGENCY 10%</b>			<b>2,835</b>
	<b>\$53,800</b>	<b>\$2,499</b>	<b>\$32,806</b>

Note: This does not include fees for daily community programs, nor administrative costs.

Taken from:  
*Indiana Mental Retardation Residential Services Planning Project, Final Report, June, 1972.*

## Appendix B

### PLANNING BUDGET OF EXPENSES FOR 6 ADULT GROUP HOMES

	Annual Operation
<b>Housing</b> (5 bedroom, 9 room and basement)	
Rent or Lease	\$ 3,000
Furnishings and equipment (est. \$1000 per room)	donated?
Heat	240
Electricity	240
Water and Sewer	120
Phone	120
Repairs and maintenance (2½%)	750
Repair and replacement of furniture and equipment (10 year life or 1/10 of \$8000)	800
Household supplies @ \$70 per month (non-food)	840
<b>Management</b>	
Live-in house-parent couple receive board and room and \$400 per month (260 days @ \$18.46)	4,800
Relief "parents" for equivalent of 2 days per week and 1 week house-parent vacation (111 days @ \$16.00)	1,776
<b>Personal</b>	
Food — \$1.50 per person per day x 8 persons = \$12 daily	4,380
Clothing for 6 @ \$180 per year	1,080
<b>Health Care</b>	
Medical (Group Plan)	
\$150 each x 8 = \$1,200	
Physician (outpatient, \$50 x 6)	1,500
Dental, \$40 x 6	240
Special Services i.e. legal, therapy (e.g. psychotherapy, speech)	683
Recreation, entertainment, contributions @ \$1 per day per person x 6 (allowances)	2,190
Transportation (to and from work, recreation, etc.) 9-passenger van	
Repairs, insurance, gas, oil — 12,000 miles @ 7¢	840
Replacement fund, 12,000 miles @ 7¢ (replace every four years)	840
Sundry @ \$8 per month x 6 = \$48 per month (i.e. toothpaste, curlers, magazines, haircuts)	576
<b>Fixed Expense</b>	
Insurance (house, contents, liability, group life). \$150 + \$600	750
Total	\$25,765
Miscellaneous and emergency (10%)	2,577
<b>TOTAL ANNUAL OPERATING</b>	<b>\$28,342</b>
Per Resident = \$4724 Annually, \$394 Monthly, \$12.95 per day	

### PLANNING BUDGET OF EXPENSES FOR CHILD AND ADOLESCENT DEVELOPMENT HOME FOR SIX INDIVIDUALS

<b>Management:</b>	
Live in houseparents (couple) — board and room plus salary of \$400 per month	\$ 4,800
Relief houseparents	2,400
Fringe Benefits (Social Security, Insurance, etc.)	720
	<b>\$ 7,920</b>
<b>Housing:</b>	
Mortgage payment or rent	\$ 3,000
Insurance (fire, liability, etc.)	720
Heat	250
Utilities (Electricity, gas, water, sewer)	500
Phone	180
Supplies	300
Repairs and Replacement of furniture (10 year life)	800
Repairs and Maintenance (2½%)	750
	<b>\$ 6,500</b>
<b>Personal:</b>	
Food (\$1.50 per person per day)	\$ 4,380
Clothing (\$200 per person per year)	1,200
Health Care (Insurance, dental, optical — \$280/yr)	1,680
Recreation (\$10 per person per month)	720
Other client expenses (\$8 per person per month)	578
	<b>\$ 8,558</b>
<b>SUB TOTAL</b>	<b>\$22,978</b>
Miscellaneous and Emergency (10%)	2,297
Transportation (12,000 miles at 12.5¢ per mile)	1,500
<b>GRAND TOTAL</b>	<b>\$26,775</b>
Annual Costs per resident	\$4,462.50
Monthly Costs per resident	\$ 371.87
Per Diem Costs per resident	\$ 12.39

Taken from:

A Comprehensive Residential Services Plan for St. Joseph County, South Bend, Indiana.

## Appendix B

### PLANNING BUDGET OF EXPENSES FOR SHELTERED LIVING HOME FOR EIGHT

#### Management:

Live in houseparent (couple) – board and room plus salary of \$400 per month	\$ 4,800
Houseparent assistants (evening and weekends, \$2.00 per hour for 20 hours a week)	2,000
Relief houseparents	2,400
Fringe Benefits (Social Security, Insurance, etc.)	920
	<b>\$10,120</b>

#### Housing:

Mortgage payment or rent	\$ 3,000
Insurance (Liability, fire, etc.)	720
Heat	250
Utilities (gas, electricity, water, sewer, phone)	680
Supplies	350
Repairs and replacement of furniture	1,000
Repairs and Maintenance	750
	<b>\$ 6,750</b>

#### Personal:

Food (\$1.50 per person per day)	\$ 5,475
Clothing (\$200 per person per year)	1,600
Health Care (Insurance, dental, optical – \$280/yr.)	2,240
Recreation (\$1 per person per day)	2,920
Other client expenses (\$8 per person per month)	768
	<b>\$13,003</b>

#### SUB TOTAL

Emergency and Miscellaneous (10%)	\$29,873
Transportation (12,000 miles at 12.5¢ per mile)	2,987
	1,500
<b>TOTAL ANNUAL OPERATING</b>	<b>\$34,360</b>

Annual Cost per resident	\$4,295.00
Monthly Cost per resident	\$ 357.91
Per Diem Cost	\$ 11.93

### PLANNING BUDGET OF EXPENSES FOR APARTMENT LIVING TRAINING UNIT FOR SIX INDIVIDUALS

#### Management

Resident apartment living trainer (Apt. + \$333/month)	\$ 4,000
Fringe benefits (Social Security, Insurance)	400
	<b>\$ 4,400</b>

#### Housing

Rental of four apartments at \$175/month each	\$ 8,400
Phone	720
Supplies	300
	<b>\$ 9,420</b>

#### Personal

Food (\$1.50 per person per day)	\$ 3,285
Clothing (\$200 per person per year)	1,200
Health Care (Insurance, dental, optical \$280/yr.)	1,680
Recreation (\$1 per person per day)	2,190
Other client needs (\$8 per person per month)	576
	<b>\$ 8,931</b>

#### SUB TOTAL

Miscellaneous and Emergency	\$22,751
Transportation (12,000 miles at 12.5¢ per mile)	1,000
	1,500
<b>TOTAL ANNUAL OPERATING</b>	<b>\$25,251</b>

Annual Cost per resident	\$4,208.50
Monthly Cost per resident	\$ 350.72
Per Diem Cost	\$ 11.69

### PLANNING BUDGET OF EXPENSES FOR SKILLS DEVELOPMENT FACILITY FOR EIGHT RESIDENTS

#### Management:

Director (behavior development and modification specialist)	\$ 9,000
Live in houseparents (couple) – board and room plus salary of \$500 per month	6,000
Houseparent assistants (students – \$2.00 per hour for equivalent of 80 hours per week)	8,320
Relief Houseparents	3,000
Fringe Benefits (Social Security, Insurance, etc.)	2,630
	<b>\$28,950</b>

#### Housing:

Mortgage payment or rent	\$ 3,000
Insurance (Liability, fire, etc.)	720
Heat	250
Utilities (gas, water, electricity, sewer)	500
Phone	180
Supplies	300
Repairs and Replacement of furniture (5 yrs. life)	1,600
Repairs and Maintenance	1,000
	<b>\$ 7,550</b>

#### Personal:

Food (\$1.50 per person per day)	\$ 5,475
Clothing (\$400 per person per year)	3,200
Health Care (Insurance, dental, optical – \$280/yr.)	2,240
Recreation (\$10 per person per month)	960
Other Client Needs (\$16 per person per month)	1,535
	<b>\$13,410</b>

#### SUB TOTAL

Miscellaneous and Emergency (10%)	\$49,910
Transportation (12,000 miles at 12.5¢ per mile)	4,990
	1,500
<b>TOTAL ANNUAL OPERATING</b>	<b>\$56,400</b>

Annual Cost per resident	\$7,050.00
Monthly Cost per resident	\$ 587.50
Per Diem Cost	\$ 19.58

### PLANNING BUDGET OF EXPENSES FOR APARTMENT LIVING UNIT (FIVE APARTMENTS) FOR TEN INDIVIDUALS

#### Management

Supervisor (or half time case worker)	\$ 4,000
Fringe Benefits (Social Security, Insurance)	400
	<b>\$ 4,400</b>

#### Housing

Rental of five apartments at \$175/month each	10,500
Phones	900
Supplies	500
	<b>\$11,900</b>

#### Personal

Food (\$1.50 per person per day)	5,475
Clothing (\$200 per person per year)	2,000
Health Care (Insurance, dental, optical – \$280/yr.)	2,800
Recreation (\$1 per person per day)	3,650
Other client needs (\$8 per person per month)	960
	<b>\$14,885</b>

#### SUB TOTAL

Miscellaneous and Emergency	\$31,285
Transportation (\$1 per person per day)	1,100
	3,650
<b>TOTAL ANNUAL OPERATING</b>	<b>\$35,835</b>

Annual cost per resident	\$3,583.50
Monthly cost per resident	\$ 298.62
Per Diem cost	\$ 9.95

## Appendix B

### ASSUMPTIONS USED IN THE BUDGET ANALYSIS I

1. 9 units, 8 of which are used for 16 residents, and 1 for the house parents.
2. The estimate annual rate for "house parents" will be \$7,200.00 or \$600.00 per month.
3. All furniture and appliances are either built-in as a part of the mortgage, paid for by the sponsor, or donated.
4. Clothes are paid for by the sponsor, parents, or the resident's income.
5. Miscellaneous administrative expenses are higher than the average per unit cost. Greater weight was given to actual data taken from Community Living Center, Inc.
6. Operating Expenses are likewise higher per unit for the same reason as #5 above.
7. Maintenance and repair expenses are also higher. This is to avoid the programming in of free or donated services that may or may not materialize.
8. It is not assumed that tax abatement will be granted. Real Estate Taxes are estimated at \$300/unit on assessed value of \$5,000/unit.
9. Debt Service and Reserve requirements are fixed by computer calculations.
10. Residents are optimally selected to insure 100% of residents are working or in a programmed activity 40 hours per week.
11. Budget for part-time professional help is only that portion of annual salaries of social workers, aids, and Residential Program Director, that is attributed to a 9 unit facility serving 16 residents.
12. A non-profit corporation is sponsoring a cluster of these 9 unit facility. A cluster is defined as 4 or 5 projects.
13. The non-profit corporation will raise sufficient funds to support its staff costs and expenses that are not covered by the part-time professional staff expenses from each project.

### BUDGET ANALYSIS I (for 9 units)

<b>Shelter Costs</b>	
House Parent Management (20% of Shelter Cost)	\$ 2,700.00
Miscellaneous Administrative (111/unit)	1,000.00
Operating Expenses (330/unit)	2,970.00
Maintenance and Repair Expenses (120/unit)	1,080.00
Real Estate Taxes (300/unit)	2,700.00
Debt Service (529/unit)	4,761.00
Reserves (Operating and Replacement) (110/unit)	990.00
Sub Total (35%)	\$16,021.00

Or a per diem rate of \$2.80/person/day

<b>Non-Shelter Cost</b>	
House Parents Supervision	4,500.00
Operating Personnel (833/unit)	7,500.00
Part-time Professional Staff (450/unit)	4,050.00
Payroll Taxes (7%)	1,124.00
Food and Supplies (1.50/person/day)	9,855.00
Miscellaneous Administrative Expenses (80/unit)	720.00
Transportation (300/unit)	2,700.00
Sub Total (65%)	\$30,449.00

Or a per diem rate of \$5.20/person/day

Total (100%)	\$46,650.00
Income \$8 per diem rate, for 16 res. 365 days	\$46,720.00

### ASSUMPTIONS USED IN BUDGET ANALYSIS II

1. 9 units, 8 of which are used for 16 residents, and 1 for the house parent.
2. The estimate annual rate for house parents will be \$7,200.00 or \$600.00 per month.
3. All furniture and appliances are either built-in as a part of the mortgage, paid for by the sponsor, or donated.
4. Clothes are paid for by the sponsor, parents, or the resident's income.
5. Miscellaneous administrative expenses are higher than the average per unit cost. Greater weight was given to actual data taken from Community Living Center, Inc.
6. Operating Expenses are likewise higher per unit for the same reason as #5 above.
7. Maintenance and repair expenses are also higher. This is to avoid the programming in of free or donated services that may or may not materialize.
8. It is not assumed that tax abatement will be granted. Real Estate Taxes are estimated at \$300/unit on assessed value of \$5,000/unit.
9. Debt Service and Reserve requirements are fixed by computer calculations.
10. Not all of the residents are working or in a programmed activity 40 hours per week.
11. The non-profit corporation maintains a staff of:
 

House parents	\$ 7,200.00
Residential Director	12,000.00
Social Worker	8,000.00
Aide and/or Secretary	5,650.00
12. The non-profit corporation sponsors only one of these homes.
13. The non-profit corporation will raise sufficient funds to support its staff costs and expenses that are not covered by the professional staff expenses from the home's budget.

### BUDGET ANALYSIS II (for 9 units)

<b>Shelter Costs</b>	
House Parent Management (20% of Shelter Cost)	\$ 2,700.00
Miscellaneous Administrative (111/unit)	1,000.00
Operating Expenses (330/unit)	2,970.00
Maintenance and Repair Expenses (120/unit)	1,080.00
Real Estate Taxes (300/unit)	2,700.00
Debt Service (529/unit)	4,761.00
Reserves (Operating and Replacement) (110/unit)	990.00
Sub Total (23%)	\$16,201.00

Or a per diem rate of \$2.76/person/day

<b>Non-Shelter Cost</b>	
House Parents Supervision	4,500.00
Operating Personnel (833/unit)	7,500.00
Professional Staff (2850/unit)	25,650.00
Payroll Taxes (7%)	2,825.00
Food and Supplies (1.50/person/day)	9,855.00
Miscellaneous Administrative Expenses (80/unit)	720.00
Transportation (300/unit)	2,700.00
Sub Total (77%)	\$53,750.00

Or a per diem rate of \$9.24/person/day

Total (100%)	\$69,951.00
Income \$12 per diem rate, for 16 res. 365 days	\$70,060.00

Taken from:

The MSHDA-N.P. Residential Program for the AMR Report. OASIS Corporation (Michigan) June, 1972.



## Appendix B

### ASSUMPTIONS USED IN THE BUDGET ANALYSIS III

- Based on 9 units, 8 of which are used for 16 residents, and 1 for the House Parent/Residential Director.
- The estimate annual rates for the staff are as follows:  
House Parent/Residential Director \$12,000  
Social Worker/Secretary 8,000  
Operating Personnel 5,000
- All furniture and appliances are either built-in as a part of the mortgage, paid for by the non-profit sponsor or donated to the home.
- It is not assumed that tax abatement will be granted. Real Estate Taxes are estimated at \$300/unit on assessed value of \$5,000/unit.
- Debt Service and Reserve requirements are fixed by MSHDA's computer calculations.
- Residents are optimally selected to insure at least 14 of the 16 residents are working or in a programmed activity 40 hours per week.
- This 9 unit home could "stand alone" as the only home that is sponsored by the non-profit corporation.
- If more than one home is sponsored by the non-profit corporation, the clustering of homes will provide economics of scale that may lead to a reduction of the per diem rate and still maintain the quality of home desired.
- The non-profit corporation will raise sufficient funds to support any additional staff and expenses that are not covered by this budget.
- Clothing is paid for by the sponsor, parents, or the resident's income.

### BUDGET ANALYSIS III (for 9 units)

#### Shelter Costs

House Parent Management (20% of Shelter Cost)	2,700.00
Miscellaneous Administrative (111/unit)	1,000.00
Operating Expenses (330/unit)	2,970.00
Maintenance and Repair Expenses (120/unit)	1,080.00
Real Estate Taxes (300/unit)	2,700.00
Debt Service (529/unit)	4,761.00
Reserves (Operating and Replacement) (110/unit)	990.00
Sub Total (28%)	\$16,201.00

Or a per diem rate of \$2.78/person/day

#### Non-Shelter Cost

House Parent/Residential Director	9,300.00
Operating Personnel (833/unit)	7,500.00
Professional Staff of Social Worker/Secretary (889/unit)	8,000.00
Payroll Taxes (7%)	1,925.00
Food and Supplies (1.50/person/day)	9,855.00
Miscellaneous Administrative Expenses (200/unit)	1,800.00
Transportation (350/unit)	3,150.00
Sub Total (72%)	\$41,530.00

Or a per diem rate of \$7.11/person/day

Total (100%)	\$57,731.00
Income \$10 per diem rate, for 16 res. 365 days	\$58,400.00

### LINE ITEM DESCRIPTION

#### Shelter Costs

##### House Parent Management.

- Previously defined as "House Parents" in the MR field, and as "Management" in the 236 housing developments.
- For shelter cost, we allocate that portion of this person's time spent on the running of the physical facility. Functions such as rent collection and deposits, payment of bills, minor maintenance, and in general, property management.
- It is estimated that 20% of the shelter cost should be allocated for this management function, as opposed to 5-7% of total income in the 236 program.

##### Miscellaneous Administrative:

- Administrative (as defined by MSHDA computer program)
- Legal and audit expenses
- Miscellaneous administrative expenses

##### Operating Expenses

- Fuel
- Water and sewage
- Insurance
- Electricity
- Miscellaneous (as defined by MSHDA computer program)
- Vacancy reserve
- Trash and snow removal

##### Maintenance and Repair Expenses:

- Maintenance (as defined by MSHDA computer program)
- Repairs

##### Real Estate Taxes: Self explanatory

##### Debt Service: Self explanatory

##### Reserves (Operating and Replacement): Self explanatory

#### Non-Shelter Costs

##### House Parent/Residential Director

- Functions performed by the resident house parents that are not directly accounted for in financial and property management of the physical facility.
- Use the balance obtained by subtracting the "House Parent Management" cost (20% of shelter cost) from the House Parent's total annual salary

##### Operating Personnel:

- Cooks
- Housekeepers

##### Professional Staff of a Social Worker/Secretary

- Social Worker and Secretary functions that are needed to provide the Home services that are not provided by the house parent.
- Assume secretarial duties of the non-profit sponsor corporation.

##### Payroll Taxes:

- 5.2% for corporate share of FICA taxes
- Unemployment taxes
- MESC taxes

##### Food and Supplies

- Food (excluding preparation)
- Items that are disposable but not edible, such as paper products

##### Miscellaneous Administrative Expenses:

- Telephone
- Travel
- Mailing and printing
- Trade dues
- Office expenses
- Primarily expenses for the non-profit sponsor corporation

##### Transportation

- Vehicle payments
- Contract transportation service
- Public transportation
- Gas and oil
- Automobile maintenance

# The Right to Choose

